A qualitative study on the experience of return to work following treatment for head and neck cancer survivors

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MAIN THESIS

&

SERVICE EVALUATION PROJECT

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This work is dedicated to
all those who survive life's impediments
to experience delayed gratification

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Main Thesis

A QUALITATIVE STUDY ON THE EXPERIENCE OF RETURN TO WORK FOLLOWING TREATMENT FOR HEAD AND NECK CANCER SURVIVORS

Supervisors: Dr Beth Grunfeld and Professor Paul Chadwick

ABSTRACT

"Anyone who can walk to the welfare office can walk to work"
Al Capp

The aim of this study was to use a qualitative approach to explore the experience of head and neck cancer (HNC) survivors upon return to work over a 1-year period post-treatment. Seventy-nine semi-structured interviews were conducted at two different timepoints, four weeks after treatment (47 interviews) and twelve months later (32 interviews). The interviews were transcribed verbatim and analyzed using thematic analysis; this work was facilitated by the NVivo 8. At these two timepoints, a number of themes emerged such as the main reasons for returning to employment and the difficulties that HNC survivors experience, the value placed on work prior to and after cancer, and work- or life-related goals following treatment. Variations in the experience among respondents shed light on the interaction between patients' post-treatment health condition and the quality of support from environmental structures such as the health care system and their workplace. These insights allowed suggestions on potential interventions that could amend the current vocational rehabilitation system provided to HNC survivors, thereby increasing their chances for a successful reintegration at work. The increased survival figures of patients surviving cancer and returning to work has significant implications on the workforce and economy, thus these suggestions can provide a valuable source of information to support the government's efforts to provide optimal care and assist people with medical problems in returning successfully to employment. Limitations of the present study are discussed and suggestions for further research projects on this area are also presented.

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CHAPTER 1

INTRODUCTION

This chapter presents the literature review. Initially, this section provides an overview on the definition of head and neck cancer (HNC), its epidemiology, aetiology diagnosis and prognosis as well as treatment options. The chapter continues with post-treatment physical and psychological issues with emphasis on the return to work experience for mixed type cancer survivors but also for HNC survivors in particular via selected studies. This review does not claim to be systematic, its aim was to set up the frame within which the rationale of this study emerged. In other words, it explored the experiences of cancer survivors regarding return to employment and illustrated the gaps in our knowledge within this sector for HNC survivors in particular.

The narrative approach (Cronin, Ryan and Coughlan, 2008) was chosen to present the literature review. Firstly, in comparison to a systematic review, a narrative review can tackle broader questions by focusing on patterns and connections among findings. Secondly, if existing data were inadequate to answer the question of interest, it permits conclusions to be drawn to direct the efforts of the present research project (see Baumeister and Leary, 1997 for more details).

The relevant literature was identified based on the following strategy. Background information such as definition of HNC, epidemiology, aetiology, diagnosis and prognosis was drawn from textbooks on HNC whereas information on post-treatment physical and psychological issues for cancer survivors as well as their return to work experience was identified through PsycInfo and Medline databases. Key search terms were used to identify the relevant research papers including “cancer survivors”, “head

and neck cancer survivors", "return to work", "continuation of employment", and "factors predicting return to work". The literature review included studies which presented both negative as well as positive experiences of cancer survivors who returned to employment. The selected studies also employed diverse methodologies; for example, quantitative and/or qualitative designs, recruitment of mixed cancer types survivors or HNC survivors only. This review will conclude by critiquing the methodology, the included patient samples, and the conclusions of the included studies.

The chapter concludes by stating the aims of the current study along with its methodological parameters.

1.1 HEAD AND NECK CANCER

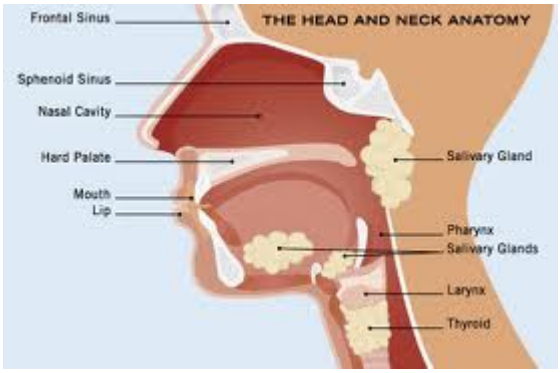
1.1.1. Definition

Cancers take their name from the organ or cell type in which the cancer growth begins (e.g. breast cancer) and cancer types can be grouped into broader categories (Ramzi, Vinay, Tucker, 1999). For example, carcinoma refers to a cancer that begins in the skin or in tissues around the internal organs; sarcoma refers to cancer which begins in connective or supportive tissue; leukemia starts in blood-forming tissue; lymphoma and myeloma refer to cancers within the immune system cells; and central nervous system cancers are refer to cancers which start in the tissues of the brain and the spinal cord.

Head and neck cancer refers to neoplasms in the head and neck regions excluding the eyes and the brain (Harrison and Sessions, 2004). There are different histopathological types, yet the most common is squamous cell carcinoma. The latter originates from the epithelium, namely the mucosal lining of the diverse structures where tumours initially develop and then

follow different courses. The affected anatomical sites can be the nasal passages, lips, mouth, tongue, pharynx, larynx, salivary glands, thyroid gland, and parathyroid gland (Figure 1).

Figure 1: Head and neck anatomy



Picture adapted from http://www.cancertreatment-wecareindia.com/

Vital functions are associated with these structures such as speech, swallowing, taste and smell. Thus, head and neck cancers, depending on the site where they originate, usually present signs that seem innocuous initially but that persist and eventually lead to symptoms such as hoarseness (44%), dysphagia (38%), continuous sore throat, local pain and painful swallowing (53%), lump in neck that does not heal (46%), referred pain such as unilateral earache (26%) and occasionally numbness or paralysis of the face muscles following cranial nerve dysfunction (1%) (Dolan, Vaughan, Fuleihan, 1998)

1.1.2. Epidemiology

The worldwide incidence of HNC ranks *tenth* of all cancers but it is the *seventh* most common cause of cancer induced mortality (WHO, 2008). Almost 600,000 new cases of head and neck cancer and 300,000 deaths occur worldwide each year (Ferlay, Bray, Pisani, Parkin, 2004). In UK, the average national incidence rates vary from 0.39 per 100,000 population for nasopharyngeal cancer to 3.01 for laryngeal cancer and 3.02 for oral cancer (OCIU, 2010). Noticeable differences in incidence rates exist between

different geographical, and thus ethnic and socio-economic regions as well as between males and females. In the developing world head and neck cancer is responsible for 12% of cancers in males and 7% in females while in developed countries the figures are 7% and 2% respectively (Sankaranarayanan, Masuyer, Swaminathan, Ferlay, Whelan, 1998).

1.1.3. Aetiological factors

Head and neck cancer etiology is multi-factorial and exhibits considerable inter-individual variation.

The principle risk factor is tobacco use in its different forms such as smoking (IARC publication 1986), smokeless products, for example betel quid (Jeng, 2001) and chewing which is a common practice in many parts of Asia and India (Winn 1992). In most instances, the dose of smoking is linearly related to the excess risk and a review indicated cancer risks of 5- to 25-fold higher for heavy smokers relative to nonsmokers (Rothman, Cann, Flanders, et al, 1980). Alcohol ingestion is also considered a common risk factor for head and neck cancer (Grønback 1998; Vokes, 1993; Spitz, 1994). Non smokers who have three or more alcoholic drinks such as beer or spirits a day have double the risk of developing HNC compared to non-drinkers (odds ratio 2,04, 95% confidence interval 1.29 to 3.21) (Purdue et al, 2009; Hashibe et al, 2007). These two agents, tobacco and alcohol, if consumed in combination throughout time strongly enhance the risk of head and neck cancer development (Rothman and Keller, 1972; Craddock, 1993; Andre, Schraub, Mercier, Bontemps, 1999; Murata 1996). Together they account for about 75% of cases (Conway, Hashibe, Boffetta, Wunsch-Filho, Muscat, La Vecchia and Winn, 2009). Continued consumption following treatment for head and neck cancer increases the risk of recurrence (Benninger, Gillen, Thieme, Jacobson, Dragovich, 1994; Rothman and Keller 1972; Silverman, Gorsky, Greenspan, 1983; Stevens, Gardner, Parkin, Johnson, 1983), the possibility of

a secondary HNC (Moore 1971; Wynder, Dodo, Bloch, Gantt, Moore, 1969) and reduces disease-specific survival (Browman, Wong, Hodson, Sathya, Russell, McApline, Skingley, Levine, 1993b; Stevens et al, 1983).

Head and neck cancers at particular sites are associated with different aetiological factors. For example, exposure to radiation increases the risk for certain types of thyroid cancer (Wartofsky, 2010). Epstein-Barr virus infection is a risk factor for nasopharyngeal cancer (D'Costa, Sarahath, Sanghvi and Mehta, 1998; Kobayashi, Shima, Saito, Kiyoshima, Matsuo, Ozeki, Ohishi, Sakai, 1999) and so are dietary factors such as vitamin deficiency (Davis 1998) and the excessive consumption of processed meat and red meat while consumption of raw and cooked vegetables seemed to be protective (Levi, Pasche, La Vecchia, Lucchini, Franceschi, Monnier, 1998). Human papillomavirus (HPV), in particular HPV16, is a causal factor for oropharyngeal cancer (D'Souza, Kreimer, Viscidi, Pawlita, Fakhry, Koch, Westra, Gillison, 2007).

1.1.4. Diagnosis and Prognosis

Physical examination, diagnostic imaging studies and pathologic review enable the clinician to investigate and diagnose a head and neck cancer. The results of these procedures will determine a number of prognostic factors, which have been shown to influence response to therapy and eventual outcome. These factors are the size and extent of the primary tumour, the status of cervical lymph nodes, and the existence of distant metastatic disease, thus generating an accurate tumour, node and metastasis stage for each patient (Benjamin, Smith and Bruce, Jaffty, 2004). The same authors reported that additional prognostic factors include patient demographics such as age, sex, race, alcohol and tobacco consumption, and the patient's general medical condition (e.g. comorbidities).

The 5-year survival for all stages of head and neck cancer is 35% to 50%. It is believed that this rate is due, at least in part to late presentation since advanced stages of the disease tend to have lower survival rates (Otto 2001; Carvalho, Nishimoto, Califano, Kowalski, 2005). Therefore, the importance of patient education and regular screening by dentists and doctors is currently being emphasized if there is to be a shift in patient survival figures. Despite advances in treatment modalities, the 5-year mortality rate for head and neck cancer has not altered significantly in the last few decades (Kurtulmaz, 1997). However, to date the clinical extent of disease seems to be the most important prognostic factor affecting outcome of treatment (Doweck, Denys, Robbins, 2002; Knegjens, Hauptmann, Pameijer, Balm, Hoebers, de Bois, Kaanders, van Herpen, Verhoef, Wijers, Wiggenraad, Buter, Rasch, 2011).

1.1.5. Treatment modalities

Surgical resection and radiotherapy, often in combination are the mainstays of treatment for most head and neck cancers and remain the standard of care in most cases (Souhami and Tobias, 2005; Spence and Johnston, 2001). Chemotherapy is often used as an adjuvant to radiotherapy with or without surgery to shrink tumours but is more commonly given as palliative treatment to patients whose cancers have not responded to surgical removal or radiotherapy. Laser surgery is increasingly being used with a spectrum of treatment aims, ranging from palliative management to primary treatment modality where it allows removal of tumours that are not reachable with robotic surgery.

All of these types of treatments have their own toxicities and adverse side effects (e.g. Machtay, Moughan, Trotti, Garden, Weber, Cooper, Forastiere, Ang, 2008) which are often intensified when used in combination (e.g. Wendt, Grabenbauer, Rödel, Thiel, Aydin, Rohloff, Wustrow, Iro, Popella,

Schalhorn, 1998). This is of particular interest because these treatment effects might impact on different aspects of cancer survivors' everyday lives, including their return to work. For example, most individuals following surgery, radiation therapy, or chemotherapy may need temporary reassignment to more sedentary duties due to weakness and fatigue and accommodations for restricted vocal capabilities and/or swallowing difficulties.

However, recent scientific advances, for example in radiotherapy and reconstructive surgery, minimize the side effects of treatment and provide patients with better functioning thus improving their quality of life as well as survival (e.g. Comet and Lartigau, 2010). Therefore, decisions about treatment are usually complex as they must take into account patients' choice as well as balance efficacy of treatment and likelihood of survival, with potential functional and quality of life outcomes.

1.1.6. Post-treatment physical and psychological issues

Head and neck cancer can present great challenges to patients who survive. Clinicians have come to acknowledge that the physical health and psychological well-being of these patients, especially following antineoplastic therapies (i.e. chemotherapy), impacts on the quality of patients' lives, regardless whether the tumour has been eradicated or controlled (de Boer, Mccormick, Pruyn, Ryckman and van den Borne, 1999). For this reason, head and neck cancer has been described as a psychologically highly traumatic cancer type (Pattison, 1967; Koster and Bergsma, 1990).

Physical side effects that persist following treatment may have long-term disabling effects for head and neck cancer survivors. In a comprehensive literature review it was reported that the most common physical side effects

of head and neck cancer survivors are problems with speech, difficulties with swallowing, dry mouth and throat and pain (de Boer et al, 1999). In particular shoulder and back pain were perceived as the most common general side effects of patients with oral and pharyngeal cancer (Langius, 1993). Pain's impact on psychiatric distress is also well-documented. Spiegel, Sands and Koopman (1994) described how pain can result in depression and anxiety which in turn impedes adjustment to chronic pain and can make the subjective experience of cancer pain more severe. Furthermore, patients who undergo radiation therapy after surgery report the most physical difficulties, which remain even at 1-year follow-up (Krouse, Krouse, Fabian, 1989).

Following a diagnosis of cancer, the meaning of health and life itself can change (Vachon, 2001) while cancer survivors face ongoing struggles to achieve a balance in their lives and a sense of wholeness and life purpose (Ferrel, 2004). Thus, psychological distress in its different forms of presentation such as depression and anxiety, accompanied by disturbances in psychosocial functioning, are common experiences for HNC survivors (Hutton and Williams, 2001).

In particular, studies have found that patients with HNC have some of the highest rates of depression and anxiety symptoms of any tumor type (Pruyn, de Jong, Bosman, van Poppel, van Den Borne, Ryckman, de Meij, 1986; Zabora, Brintzenhofeszoc, Curbow, Hooker, Piantadosi, 2001; Massie 2004; Van't Spijker, Trijsburg, Duivenvoorden, 1997). In patients with HNC, rates ranging from 19% to 40% of both clinically significant depression symptoms (Akech, Nakano, Okamura, Ueda, Akizuki, Nakanishi, Yoshikawa, Matsuki, Hirabayashi, Uchitomi, 2001; Katz, Kopek, Waldron, Devins, Tomlinson, 2004; Kugaya, Akechi, Okuyama, Nakano, Mikami, Okamura, Uchitomi, 2000; Hammerlid, Ahlner-Elmqvist, Bjordal, Biörklund, Evensen, Boysen, Jannert, Kaasa, Sullivan, Westin, 1999; Humphris, Rogers,

McNally, Lee-Jones, Brown, Vaughan, 2003; Hutton and Williams, 2001) as well as anxiety symptoms (Hammerlid et al, 1999; Humphris et al, 2003) have been documented.

In addition, suicide rates are higher among cancer patients than the general population (Allebeck and Bolund, 1991; Bolund, 1985; Dhooper, 1985; Björkenstam, Edberg, Ayoubi, Rosén, 2005). Björkenstam and colleagues (2005) found that the suicide rate ratio between male cancer patients and the general population was about 1.5 in 1985-1994 while among female cancer patients was 2.3 for the same period. It was also reported that suicide rates are higher in patients with larynx tumour (Faberow, Ganzler, Cutter, Reynolds, 1971), pharyngeal cancer (Bolund, 1985) and oral cavity tumour (Faberow et al, 1971; Bolund, 1985). This is particularly true for severe cancer sites with low survival rates (Björkenstam et al, 2005).

Furthermore, among HNC patients, social anxiety symptoms (Ackerstaff, Lindeboom, Balm, Kroon, Tan, Hilgers, 1998) and post-traumatic stress disorder symptoms (Chen, Lai, Liao, Lin, 2005) may be more frequent than in people with other forms of cancer. In a cross-sectional survey of 204 patients 7-11 years after curative radiation therapy, it was identified that psychological distress was significantly associated with impaired cognitive function, reduced social well-being and pain (Bjordal and Kaasa, 1995). In a study examining depression and anxiety, Hassanein, Musgrove and Bradbury (2001) showed that they are both related to poor function in usual activities such as self-care and jobs are discontinued resulting in social isolation.

Fear of recurrence is considered another significant psychological problem for cancer survivors, which is often persisting and highly distressing (Herschbach, Book, Dinkel, et al, 2010). In other words, survivors fear or

worry that cancer will return or metastasise (Simard, Savard, Ivers, 2010; Vickberg, 2003) It is estimated that between 22% and 99% of cancer survivors experience fear of recurrence (Simard et al, 2010) and it often predicts poorer quality of life outcomes up to 6 years post diagnosis (Llewellyn, Weinman, McGurk, Humphris, 2008). Crist and Grunfeld (2011) reported in their systematic review that fear of recurrence is influenced by a variety of factors such as demographic (e.g. age), clinical (e.g. physical symptoms and treatment type) and psychological factors (e.g. optimism and family stressors).

Despite the above evidence, which suggest the prominence of depression and anxiety in HNC patients, other studies have failed to replicate findings. For instance, Manuel, Roth, Keefe and Brantley (1987) found that whilst anxiety is high at diagnosis, it does reduce in severity in the course of time. Another study found that depression is not such a common feature of HNC (Morton, Davies, Baker, Baker, Stell, 1984).

Following cancer diagnosis and subsequent treatment patients often need to discontinue their usual job, house chores and other activities (de Boer et al, 1999). Studies have shown that patients who underwent laryngectomy and/or radiotherapy reduced their social activities following their therapy (Chaturvedi, Shenoy, Prasad, Senthilnathan, Premlatha, 1996; Jay, Ruddy, Cullen, 1991) which led to their social isolation (Gamba, Romano, Grosso, Tamburini, Cantú, Molinari, Ventafridda, 1992). According to Koster and Bergsma (1990), one of the main reasons was due to consequences of the aesthetic outcomes of surgery and the most pervasive problem domains were found to be communication with a partner, functioning in the family, and social and interpersonal relationships (Espie, Freedlander, Campsie, Soutar, Robertson, 1989; Rapoport, Kreitler, Chaitchik, Algor, Weissler, 1993).

Fatigue is one of the most common side effects reported by patients with cancer and this has an impact upon everyday routines and all aspects of their quality of life (Piper, 1993; Gupta, Lis, Grutsch, 2007). Krouse and his colleagues (1989) found that fatigue and weakness were the major concerns of post-surgery patients with HNC up to 12 months later. Patients reported fatigue as one of the most distressing symptoms related to cancer and its treatment (Stone, Richardson, Ream, Smith, Kerr and Kearney, 2000). In particular, patients who underwent laryngectomy and other forms of surgery often experienced symptoms of fatigue as a side effect (Jones, Lund, Howard, Greenberg, McCarthy, 1992). In addition, a systematic review by Brown and Kroenke (2009) confirmed the association of fatigue with depression and anxiety. Overall, it has been reported that 50-90% of cancer patients experienced fatigue (Stone et al, 2000; Curt, Breitbart, Cella, Groopman, Horning, Itri, Johnson, Miaskowski, Scherr, Portenoy, Vogelzang, 2000; Vogelzang, Breitbart, Cella, Curt, Groopman, Horning, Itri, Johnson, Scherr, Portenoy, 1997; Stasi, Abriani, Beccaglia, Terzoli, Amadori, 2003; Flechtner and Bottomley, 2003; Wang, Giralt, Mendoza, Engstrom, Johnson, Peterson, Broemeling, Cleeland, 2002). Fatigue may persist for months or even years after cancer treatment (Cella D, Davis K, Breitbart W, Curt, 2001). In general, fatigue is considered a difficult to manage symptom in cancer survivors (Escalante and Manzullo, 2009).

Post-treatment facial disfigurement is a significant issue among HNC survivors. Appearance may be altered as a result of visible scarring and structural changes due to surgical removal of bone and tissue, swelling or neck stoma after laryngectomy. Gamba and colleagues (1992) found that one in five patients, perceived himself or herself as changed physically regardless of the degree of disfigurement following surgery. Certain individual factors impact on disfigurement in such a way to result in distress and render effective coping more challenging. For example, people

whose identity has always been strongly associated with appearance or on their communication skills (e.g. teachers, salesmen) report poorer adjustment (Callahan 2004; Hagedoorn and Molleman 2006). This is partly related to physical appearance and partly to perceived changes in speech. However, disfigurement is a subjective experience in that the degree of distress is only weakly correlated to objective disfigurement. Furthermore, patients' ratings of postsurgical disfigurement are poorly correlated with observers' ratings (Katz, Irish, Devins, Rodin, Gullane, 2000). Regardless of the subjectivity of this experience, profound psychological trauma (Breitbart and Holland, 1988; Bronheim, 1994), reduced quality of life and increased depression (Pruyn et al, 1986; Dropkin 1999; Katz et al, 2000; Long, Robinson, Zimmerman, Petti, Chonkich, 1996) is often reported by HNC survivors.

In addition, disfigurement was found to place limits on specific areas, such as social functioning (Devins, Stam, Koopmans, 1994), and hence cause psychosocial problems in people with HNC. A study revealed that 57% of the patients interviewed perceived that they had been stigmatized because of their appearance (Strauss, 1989) and a further study showed that concerns about appearance leads to reduced social contact with family and friends (Dhooper, 1985).

Sexual function is also an issue for HNC patients (de Boer et al, 1999). A number of studies have reported that decreases in sexual contact range from 17% to 48% (Jay et al, 1991; de Boer, Pruyn, van den Borne, Knegt, Ryckman, Verwoerd, 1995; Albertini, Ferro, Lombardo, Maina, Ravizza, Bussi, 1993; Monga, Tan, Ostermann, Monga, 1997). More than 20% of initial 172 patients who went through partial or complete laryngectomy admitted sexual dysfunction (DeSanto LW, Olsen KD, Perry WC, Rohe DE, Keith RL. 1995). In addition, Maguire and his colleagues (1978) found that sexual functioning

was related to symptoms of anxiety and depression in breast cancer survivors. However, findings from another study claimed that sexuality was not a significant problem domain for patients with HNC (Rapoport et al, 1993). Yet, this depends on how these patients were asked about their sexual functioning, particularly if it was in relation to other more significant or distressing factors.

The effects of medical and functional impairments on the quality of life and the disturbances of the psychological and psychosocial functioning are known to change over time. Cancer survivors face challenges across the continuum of their cancer care (as cited in National Cancer Policy Board, 2005, p. 67). Therefore, an important element of their survivorship experience is that it is dynamic. For example, the transition from treatment to long-term follow-up or the transition from being a cancer patient in the hospital to a cancer survivor back in employment will result in different challenges.

1.1.7. Return to work

Improvements in early detection and treatment of cancer have resulted in an increasing number of cancer survivors (Spelten, Sprangers, Verbeek, 2002). This change shifted the conceptualization of cancer from a terminal illness to a chronic one for some authors whilst still others may view it as a discrete illness (Jemal, Clegg, Ward, Ries, Wu, Jamison, Wingo, Howe, Anderson, Edwards, 2004). People surviving cancer may need to amend their lifestyle but in many cases can continue or resume the activities of their everyday life during or following treatment, including their working lives.

Approximately 30% of cancer patients who are employed in the UK continue to work, in some capacity during their cancer treatment (Pryce, Munir, Haslam, 2007). For all cancers, studies have reported from 44% to

100% or survivors returning to work following long-term sick leave (Verbeek, Spelten, Kammeijer, Sprangers, 2003; Short, Vasey, Tunceli, 2005). Specifically, the ratio for survivors of HNC who continue to work after treatment is around 50-83% (Sharri, Buchbinder, Costanbtino, Lawson, Biller and Urken, 1998; List, Siston, Haraf, Schumm, Kics, Stenson and Vokes, 1999). Returning to work can foster an individual's identity and provide a social connection; it also presents a distraction and enables the person to regain a sense of returning to normality following diagnosis and treatment and allows survivors to regain a perception of control over the illness (Peteet, 2000, Steiner, Cavender, Main, Bradley, 2004) as well as reclaim financial security (Amir, Neary, Luker, 2008). Therefore, returning to work may enhance the patient's quality of life and be seen as a symbol of recovery (Steiner, Cavender, Main, Bradley 2004).

The fact that cancer survivors return to work has beneficial implications not only at an individual level but also for the workforce and economy; research indicates that cancer survivors can be productive and perform well in the workplace (Bradley and Bednarek, 2002) providing their employers accommodate their needs. Therefore, cancer has also become a significant issue for employers to address (Schultz, Beck, Stava, Sellin, 2002). An amendment of the Disability Discrimination Act (DDA) in 2005 aimed to protect most cancer patients from discrimination at work from the point of diagnosis. Employers are expected to make "reasonable adjustments" to address the needs of cancer survivors who choose to return to employment (Morell and Pryce, 2005). In addition, providing support for a successful return to work is also important because it alleviates the economic impact of cancer (Steiner et al, 2004).

Factors affecting return to work for cancer survivors

Yet, going back to work following cancer appears to be a complex process. Cancer survivors are challenged by a number of factors in order to achieve a successful return to employment. Overall, findings from a number of studies converge to indicate that successful return to work is likely to be primarily influenced by factors related to the disease, the patient's characteristics and the workplace. Each of these will be dealt with below.

With regard to factors associated with the disease, evidence indicated that these were: cancer diagnosis, disease stage and treatment type (Brown and Tai-Seale, 1992; Bloom, 1999; Spelten, Verbeek, Uitterhoeve, Ansic, van der Leilie, de Reijke, Kammeijer, de Haes, Sprangers, 2003; Greenwald, Dirks, Borgatta, McCorkle, Nevitt, Yelin 1989; Mols, Thong, Vreugdenhil, van de Poll-Franse, 2009; Taskila T and Lindbohm, 2007; Verbeek, Spelten, Kammeijer, Sprangers, 2003; Short, Vasey, Tunceli, 2005).

In particular, the employability of cancer survivors varies for different cancer diagnoses. For example, cancer of the nervous system and lung cancer were most commonly found to be associated with lower employment and work ability (Taskila et al, 2004; Short et al, 2005). The main reasons for the low employability among survivors with cancer of the nervous system appears to be the adverse side effects of the treatment as well as its high recurrence rate (Jääskeläinen, Ilveskoski, Mäenpää, Mäntylä, 1999). Among people with lung cancer the low likelihood of being employed can be explained by their low life expectancy; the relative five-year life expectancy is 10% for men and 13% or women (Mattson, Kysölä, Ojal, 1999).

Disease stage has been found to be independently associated with the ability to work for cancer patients. For example Villaverde and colleagues (2008) found that stage IV disease predicted sick leave at the beginning of

treatment; and by the end of treatment any kind of sequelae of advanced-stage disease was significantly associated with continuing sick leave. Such findings suggest that advanced-stage disease-related symptoms impact cancer survivors' employability.

Treatment type was another factor affecting employability. People treated with chemotherapy may have a higher prevalence of treatment-related side effects such as fatigue, cognitive impairment (e.g. memory, attention) and treatment-induced menopause than among survivors who underwent other types of treatments (Stewart et al, 2006; Ahler et al, 2002; Fan et al, 2005). Furthermore, these can impact on their attempt to return to work. For example, Spelten and her colleagues (2003) argued that fatigue levels alone predict how soon a person with cancer is able to return to work whereas other studies suggested that the quality of life is significantly poorer among cancer patients who suffer from treatment-related side effects and this is likely to affect their work ability.

Furthermore, it was reported that the cancer experience could result in a number of difficulties such as pain, fatigue, depression and concentration which would act as obstacles when return to work is attempted (Verbeek, et al, 2003; Maunsell, Brisson, Dubois, Lauzier, Franser, 1999). In particular, fatigue levels at 6 months were found to be related to depression, physical complaints such as headache and dizziness, sleep problems and emotional distress and were predictive of return to work at 18 months (Spelten et al, 2003). Steiner and colleagues (2008) reported that physical symptoms such as lack of energy and psychological symptoms such as feeling depressed were significantly associated with a reduction in work hours or a change in occupational role. Therefore, it was suggested that better management of cancer-related symptoms is needed to facilitate return to work (Spelten et al, 2003). In addition, the provision of information from health professionals

regarding return to work and work-related issues has been reported to play an important role (Verbeek, et al, 2003; Maunsell, Brisson, Dubois, Lauzier, Franser, 1999) as lack of such information has been shown to affect the number of people who return to work successfully.

Patients' characteristics such as age, gender, education and socioeconomic status have all been found to influence return to work (Brown and Tai-Seale, 1992; Bloom, 1999; Taskila and Lindbohm, 2007). Studies have shown that older people who have a lower level of education and work in blue-collar jobs are less likely to be employed (e.g. Taskila-Äbrandt et al, 2004; Short et al, 2005; Bradley et al, 2005). This is possibly because less educated people are more likely to work in more physically demanding jobs. Following the experience of cancer, people's physical capacity is reduced at least temporarily (Hewitt, Rowland and Yancik, 2003) and this can lead to difficulty performing some work roles. Another study showed that women after breast cancer reduced or stopped working voluntarily, possibly due to valuing career goals less and turning attention to family (Maunsell et al, 2004).

Workplace characteristics such as the physical demands of the work and challenging relationships with colleagues and supervisors were reported to have a negative impact on return and continuation of employment (Greenwald et al 1989; Berry, 1993; Ganz, Coscarelli, Fred, Kahn, Polinsky, Petersen, 1996; Satariano and De-Lorenze, 1996; Verbeek, et al, 2003; Maunsell et al 1999; Spelten et al, 2002). For example, Spelten and colleagues (2002) showed that cancer survivors with manual labour jobs and people holding jobs, which pose physical demands were less likely to return to employment. Furthermore, breast cancer survivors who reported discrimination because of their condition were less likely to return to work at 12 months (Booknight, Bradley and Luo, 2006). Therefore, it was

suggested that workplace parameters played an important role in assisting people getting back to work (Booknight et al, 2006) and thus employers appear to have a pivotal role in assisting cancer patients return successfully to employment.

There is a strong link between experience of side effects and how people cope at work. Studies have demonstrated that individuals find it difficult to manage both cancer symptoms and work demands. In fact, Pryce and colleagues (2007) argued that this often led to poorer psychological and physical health outcomes. For example, many cancer survivors report depression and anxiety (Spelten et al, 2003) which often leads to further psychological distress, poor self-esteem and poor self-management including medication adherence which may further affect their physical status (Munir et al, 2009). Also, cancer-related fatigue has been shown to have a significant effect on employment with over 75% of cancer patients forced to change their working conditions (Curt et al, 2000).

On the other hand, patients' attitude, self-efficacy and positive beliefs about their ability to return to work were reported to be strong predictors of actual return and continuation of employment (Spelten et al 2003; Taskila and Lindbohm, 2007; de Boer, Verbeek, Spelten, Uitterhoeve, Ansink, de Reijke, Kammeijer, Sprangers, van Dijk, 2008). For example, Hansen, Edlund and Henningsson (2006) showed that the most predictive factor for return to employment was individuals' expectations of the likelihood that they would return to work. Another study found that breast cancer survivors who reported a greater sense of control over their symptoms at work return earlier to full time employment (Cooper, Hankins, Rixon Eaton and Grunfeld, 2012). Therefore, it was suggested that eliciting and challenging specific cancer and treatment-related perceptions is essential as it may

facilitate return to the workplace (Cooper et al, 2012; Shaw, Segal, Polatjko and Harburn, 2002).

Furthermore, some studies indicated better return to work experience when employers provide support to employees with history of cancer (Bradley and Bednarek, 2002; Farley, Short, Vasey and BeLue, 2008). For example, Amir, Neary and Luker (2008) reported that a good employee-employer relationship has shown to relate to a positive experience of returning to employment. There is also evidence from across a range of chronic illnesses that employers who made work adjustments to accommodate functional limitations ensured that employees not only maintain their employment but also that they are better able to manage their work (Taskila and Lindbohm, 2007; Baander, Andries, Rijiken, Dekker, 2001). Work-place adjustments, such as changing work responsibilities or the provision of specialist equipment and phased returns, which offer the opportunity to return to work with a gradual reintroduction of tasks (Grunfeld, Rixon, Eaton and Cooper, 2008), represent some examples of such adjustments. This approach can help boost wellbeing and confidence (Taskila and Lindbohm, 2007). Literature examining the concerns of cancer survivors has repeatedly shown that organisations have a key role to play in the transition back to employment (Amir et al, 2008; Kennedy et al, 2007). Thus, the study by Grunfeld and colleagues (2008) that reported a serious commitment from organization to be supportive of cancer survivors returning to employment by offering a range of return to work services showed a positive response from employers to these concerns. However, if employees are inadequately informed of such services this may hinder a positive return to work experience. Thus, it is imperative that cancer survivors are provided with relevant information in order to initiate discussions with their employers regarding the type of services that would be useful for their successful return to work (Grunfeld et al, 2008). In addition, it was suggested that there

is a need to develop interventions, which target the knowledge, beliefs and skill-base of managers (Grunfeld, Low and Cooper, 2010). Managers need to be able to identify problems likely to occur when cancer survivors return to work in order to be able to provide the necessary support. This will facilitate a constructive dialogue between the employers and the employees.

Factors affecting return of work specific for HNC survivors

Few studies have investigated factors influencing return to work specifically in HNC survivors. However, it was found that patients with HNC reported more problems when attempting to return to work in comparison to other cancer survivors (e.g. Wooden et al, 1992). Specifically, it was reported that HNC survivors have the highest adjusted risk of disability or quitting work (Spelten et al, 2002; Short et al, 2005). The median time for HNC patients with different cancer sites and treatments who return to work has been reported to be 6 months after therapy (Verdonck-de Leeuw et al, 2010). Another study showed that 17.5% of HNC survivors were unable to work (Schultz et al, 2002). Overall, findings to date echo aforementioned results, in that factors influencing successful return to work were related to parameters around the disease as well as characteristics of the patients and their work environment and characteristics.

For example, a study found that certain HNC treatments (e.g. laryngectomy) rendered resumption of work more difficult because survivors had lost their ability to speak (Schraub, Bontemps, Mercier, Barthod, Fournier, 1995). They also found that high levels of anxiety and oral dysfunction (e.g. xerostomia, sticky saliva, problems with teeth) as well as loss of appetite and deteriorated social functioning were barriers for a successful return to work. List and colleagues (1999) pointed out that change in appearance is a significant reason for not returning to work after HNC treatment whilst Mast (1999) showed that patients reported that they coped more easily with

dysfunction than with disfigurement. Also, the recent work of Verdonck-de Leeuw and colleagues (2010) indicated that age and lower education were the two primary reasons that patients do not return to work. Finally, Schraub and colleagues (1995) reported that employment was related to the nature of the work prior to diagnosis, in that civil servants for example were more likely to return back to work than craftsmen (Schraub, Bontemps, Mercier, Barthod, Fournier, 1995). Thus, it appears that physical and emotional distress as well as patients' and work characteristics might draw employed HNC survivors out of their work temporarily and it may even impact on the likelihood of them returning to work.

Cancer survivors' experiences following return to work

The challenges for cancer survivors who return to employment may not be over if they manage to resume their working status. Studies show that individuals either cease to work or take early retirement because of long-standing side effects that lead to poor health or disability (e.g. Bradley and Bednarek, 2002). In particular, Buckwalter, Karnell, Smith, Christensen and Fun (2007) reported that patients discontinue work because of difficulties with fatigue, speech, eating, pain or discomfort and appearance. According to Spelten, Sprangers and Verbeek (2002), withdrawal from the workforce also occurs because a significant proportion report being demoted, earning less, having less control over their work, losing their jobs or report that their illness has damaged their work capacity.

Yet, a study by Bradley and Bednarek (2002) provided evidence that cancer survivors tend to remain employed, earn high wages and be productive, even at a level beyond the typical work week (i.e. working full-time). Although, these patients reported some degree of disability often with multiple limitations as a result of cancer and its treatment, they were able to maintain their position and competence in the workforce due to their

employers' support in accommodating their needs. However, this study did not focus on the total cancer population but on a long-term survivor population who were more likely to be diagnosed in early stages and thus their condition was considered less severe than patients diagnosed in later stages. In addition, this study was confined to a geographic region with high employment in the automobile industry, which participates in the United AutoWorkers union. Therefore, it is likely that these employees may have more generous sick leave policies and salaries than the general population of workers in smaller firms without comparable benefits who may be more economically vulnerable.

Drawing conclusions

The studies that comprised this literature review provide a basis from which one can draw conclusions regarding the current literature. For example, the included studies presented both factors impeding successful return to work (e.g. Ganz et al, 1996, Spelten et al, 2002, Pryce et al, 2007, Verdonck-de Leeuw et al, 2010, Taskila et al, 2004) and their negative consequences in survivors' working life (e.g. Spelten et al 2002) as well as factors, which facilitate employment following cancer (e.g. Spelten et al, 2003, Hansen et al, 2006, Cooper et al, 2012, Shaw et al, 2002, de Boer et al, 2008) and their positive impact on individuals (e.g. Peteet, 2000; Amir et al, 2008; Bradley and Bednarek (2002). The inclusion of these studies ensured that an unbiased overview with regards to both factors impeding and facilitating return to work was formed. Overall, studies used different methodological designs such as reviews (e.g. Spelten et al, 2002; Taskila and Lindbohm 2007), surveys and questionnaires (e.g. Steiner et al, 2008; Villaverde et al, 2008; Spelten et al, 2003; Cooper et al, 2012; Hansen et al, 2006) and qualitative methods (e.g. Shaw et al, 2002). In addition, the samples of recruited participants consisted both of patients with mixed cancer types (e.g. Taskila et al, 2004; Spelter et al, 2003; Maunsell et al 1999) as well as

HNC patients in particular (e.g. Schraub et al, 1995; Verdonck-de Leeuw and colleagues, 2010). As a result, it was possible to form a picture of the current situation related to mixed cancer patients in general as well as specifically for HNC patients. A few studies provided little detail on their methodological approach (e.g. Villaverde et al, 2008), yet, most studies provided sufficient detail on their employed methods enabling a comprehensive assessment of their research methodology and replication of their findings (e.g. Spelten et al, 2002; Cooper et al, 2012; Steiner et al, 2008). Studies applied appropriate statistical analyses on their data (e.g. Cooper et al, 2012; Spelten et al, 2002) and provided tables and figures, which were clearly describing the data allowing assessment and understanding of the results (e.g. Spelten et al, 2002; Taskila & Lindbohm, 2007; Steiner et al, 2008). Overall, most of the selected studies comprised of good sample sizes and similar cancer types using similar quantitative and qualitative approaches and thus allowing both comparison across samples as well as in depth examination within studies. Although some studies did not discuss their results in relation to similar studies (e.g. Villaverde et al, 2008; Hansen et al, 2006; Shaw et al, 2002) most presented them in context by providing a detailed discussion linking their findings with the existing literature review (e.g. Taskila et al, 2004; Steiner et al, 2008; Cooper et al, 2012). Finally, most studies provided adequate interpretation on their findings and possible explanations of their results alongside a clear discussion on limitations (e.g. Spelter et al, 2002; Cooper et al, 2012), which ensured that they met their study's objectives. The mixture of these studies ensured multidimensionality of outcomes and thus confidence in the following conclusions.

Two main conclusions can be drawn. Firstly, the majority of studies to date have focused on return to work experience with mixed cancer types and only few of them reported the specific factors of individual cancer groups. Therefore, inter-group differences are not clear. As a consequence,

knowledge of the experience of HNC survivors is limited despite the fact that work-related issues are important to this clinical group (Verdonck-de Leeuw, van Bleek, Leemans, de Bree R, 2010). Secondly, most of these studies were retrospective surveys and/or questionnaires (Pryce et al, 2007), which were completed 2-8 years following diagnosis (Taskila-Abrandt, Martikainen, Virtanen, Pukkala, Hietanen, Lindbolm, 2004). Although, this is an informative design, it has two major disadvantages. Firstly, it does not allow examination of the trajectory of change, which may be possible within a longitudinal studies. Secondly, it lacks in-depth exploration of the issues relating to successful return to work around the time when return to employment was attempted. However, prospective studies using mixed methods (with a focus on qualitative methods) can address this issue.

In summary, the increased number of people who survive cancer results in a high number of people attempting to return to their working lives and this has important implications for the wellbeing and financial security of the survivors as well as to the workforce and economy. This is also true for HNC given its 5-year survival rate for all stages and thus HNC survivors are an important clinical population to be explored.

Furthermore, previous studies indicated that cancer survivors face a number of challenges upon return to work, including long-term adverse effects of treatment and their work conditions and requirements. However, the literature review showed that despite the body of research examining return to work across mixed types of cancer, research to date focusing on the work experience of HNC survivors is limited.

In addition, current knowledge is mainly based on retrospective quantitative studies, which may miss aspects of the personal experiences of this group around the time they attempt to return to employment.

Therefore, there is an evident need to complement current literature with further in-depth and longitudinal research on the factors that are associated with successful and unsuccessful return to employment for HNC survivors. The present study tackled exactly this issue by focusing on HNC individuals who received treatment and returned to employment. Its qualitative methodological design allowed this clinical group to be studied in depth providing a clearer picture of HNC survivors' experience when they attempt to return to work.

Qualitative techniques are extremely useful for complex subjects. A qualitative study can provide an in-depth understanding on issues around return to work for HNC survivors, which are so far poorly understood. It can explore in more detail how the physical and psychological impact of treatment acts as a barrier to HNC survivors who attempt to return to employment. For this reason, it was considered a more appropriate design over quantitative research methods for the purpose of this project.

The potential output of such a study is multifaceted. It can enrich current psychological understanding of the process of return to work after HNC cancer, elucidating barriers, facilitators and factors key to the individual. It can help to contextualize return to work within a broader psychological process of adjustment to loss and change, and to an appraisal of the importance and value of work following cancer. The findings can help shape interventions and services to ensure that patients' experiences are as positive as possible. Furthermore, it can advise services aiming to help people find work (e.g. Jobcentre Plus) to help people with HNC to remain with their current employer or emphasise the urgency for governmental schemes to support in particular small to medium sized enterprises in order to incorporate Occupational Health departments in their services. In addition,

findings can be used to raise awareness amongst health and employment professionals about the rehabilitation needs of people with HNC, to help developing new standards of HNC care and integrating vocational rehabilitation into health and social care assessments.

1.2. THE CURRENT STUDY

The aim of this study was to explore HNC survivors' experience of work over a 1-year period post-treatment. In particular, the aim was to explore their beliefs and obstacles around returning to work following cancer treatment, their experience following disclosing their diagnosis to employers and the impact on their perceptions of career and life goals. A qualitative longitudinal approach was employed by conducting semi-structured interviews with HNC survivors four weeks after their treatment (T1) and a follow-up interview 12 months later (T2).

The design is intended to embrace both the complexity of individual experience of return to work, and how this process may change over time. Given that the median time for the majority of HNC survivors who return to work is around 6 months following treatment (Verdonck-de Leeuw et al, 2010), it was assumed that interviews within a month following treatment would include those contemplating a return to work, as well as those who have returned already, in order to capture the diverse motivations, worries, hopes and challenges that precede and accompany a return to work. Re-interviewing participants over the course of one year will also allow exploration of return to work as a psychological *process* of change and adjustment. It is expected that this knowledge will shed light into the elements that constitute a successful return and stay in employment following cancer experience.

Therefore, the specific research question is: what are the key themes that emerge from participants' descriptions over a 12 month period of the process of contemplating and returning to work following HNC cancer?

CHAPTER 2

METHODOLOGY

2.1 ON METHOD

This chapter sets the parameters within which the present study was set up. It explains how the study is positioned within the larger research programme, of which it was a part. Information about the patients who took part in this study along with the time points and the way they were approached, is provided. It explains how interviews were structured and how results were analyzed. Finally, it illustrates how the results are presented within the next three chapters.

2.1.1. Study context

The present study was part of a larger research programme with the ultimate aim of developing an intervention to improve return and work retention among cancer survivors. In order to ensure the implementation of validated, evidence-based interventions, two main targets were set. Firstly, to identify the factors that predict a successful return to work, and secondly, to use these results in order to develop and pilot a targeted intervention strategy. With regard to the first target, several studies were conducted to identify the factors that predict return to work across four cancer types: breast cancer, gynecological cancer, head and neck cancer and urological cancer. A questionnaire pack was administered within four weeks following treatment completion (baseline), then at 6 months and 12 months. The questionnaires looked at clinical, work-related and psychological factors and examined attitudes towards returning to work, coping, health, emotional wellbeing and beliefs about cancer. This research has been published elsewhere (Cooper et al, 2012). In addition, interviews were conducted at baseline and at 12 months to explore potentially important factors in more detail and whether changes took place over time as well as the reasons for such changes. Studies reporting the results of interviews on patients with

gynecological (Grunfeld & Cooper, 2010) or prostate cancer (Grunfeld, Drudge-Coates, Rixon, Eaton and Cooper, 2013) have also been published. The present study focused on HNC survivors' interviews.

This study explored the factors influencing return to employment for HNC survivors and identified any changes that may have taken place over time based on interviews collected at baseline and at 12 months.

Recruitment was consecutive and conducted by two research assistants using a similar verbal explanation and invitation. They also performed the interviews at both time points. The encrypted sound recordings were sent to an external transcription service. The author of this thesis did not collect nor transcribe the data as her role was to qualitatively analyze the interviews in order to understand the factors associated with successful return to employment following HNC treatment. The author's supervisor analyzed 15% of the transcripts as a reliability check.

2.1.2. Sample

Head and neck cancer survivors were eligible for inclusion in this study providing they were aged between 18 and 65 years, English speaking, had no evidence of advanced disease or recurrence and were in paid employment at the time of diagnosis. Baseline respondents' characteristics are summarized in.

Each participant's job title and nature of work was collected via an interview 4 weeks after their treatment. Self-reported job descriptions were refined if necessary and categorized into occupational groups (numbered from 1 to 9) according to descriptive labels provided in the International Standard Classification of Occupations program (ISCO 88, ILO, 1990). Using the 9 occupational group categories, further regrouping created three broad

categories: white collar (managerial and professional occupations), pink collar (clerical, sales and service occupations) and blue collar (manufacturing and materials handling, indoor and outdoors). Analysis of the categories identified in the content analysis will focus on these three occupational collar groupings.

Table 1: Characteristics of the cancer-patient sample at baseline (*n*=47)

	N	
SOCIODEMOGRAPHIC		
Age	Mean = 51 years (range 22 - 64)	
Gender		
- Male	35	75%
- Female	12	25%
Civil status		
- Married / with partner	35	75%
- Separated, divorced, widowed	5	10%
- Single	7	15%
Education		
- No academic qualifications	9	19%
- GCSE / A Level or equivalent	23	49%
- College / University	15	32%
Race / ethnicity		
- White	42	90%
- Black	3	6%
- Other	2	4%
Number of dependent children		
- None	30	64%
- 1	6	13%
- 2	4	12%
- 3 or more	5	11%
Work		
- Not working	26	55%
- Working	17	45%
- Full Time	39	83%
- Part Time	8	17%
Collar grouping		
White collar	25	53%
Pink collar	6	13%
Blue collar	16	34%
Company		
- Small	5	10%
- Medium	5	11%
- Large	28	60%
- Self-employed	9	19%
Duration of employment with company	Mean = 13 years (range .00 – 46)	
CLINICAL		
Type of cancer		
Oral cavity	16	34%
Nasopharynx	4	11%
Oropharynx	6	13%
Hypopharynx	1	12%
Larynx	5	11%
Trachea	9	19%
Stage		
- 1	6	13%
- 2	21	45%
- 3	6	12%

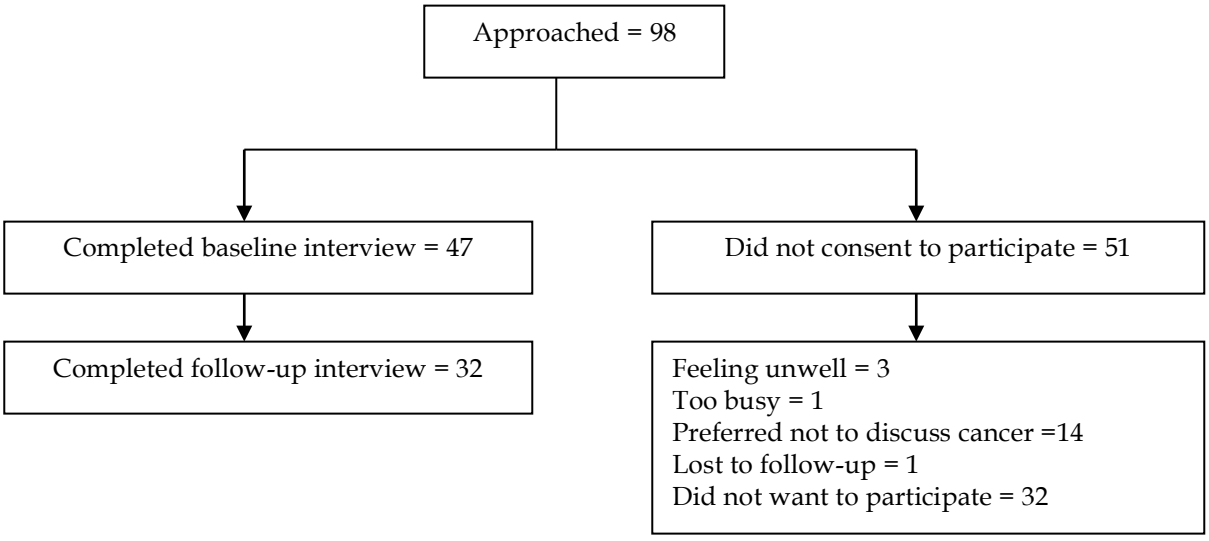
- 4	14	30%
Treatments*		
- Surgery	33	70%
- Chemotherapy	13	28%
- Radiotherapy	39	82%

* Some patients had more than one treatment

Forty-seven patients completed the baseline interview whereas 32 patients completed the follow up interview. All respondents at follow-up had been interviewed at baseline. The analysis was based on these 79 interviews.

Fifty one of the ninety-eight patients (i.e. 52%) who were approached to take part chose not to participate in the study either because they were still feeling unwell (3), were too busy (1), preferred not to discuss cancer (14), were lost to follow-up (1) or did not want to participate in the study (32), (See diagram 1).

Flow diagram 1: Recruitment for return to work study



There were no significant differences in terms of age, ethnicity, collar grouping, education level, tumour or treatment type between those who agreed to participate and those who did not.

Striking a balance between having a large enough sample size to provide rich data and avoiding ethical issues of over-recruitment is always challenging in qualitative studies. The guiding principle used to resolve this issue in qualitative studies is to cease collecting data when a saturation point is reached. In other words, when data becomes repetitive and new data does not shed any further light on the issue under investigation (Glaser and Strauss, 1967).

With regards to the present study, saturation was not used because this research was part of a larger quantitative study that used questionnaires to collect data and re-interviews were included to allow further exploration of the issues that patients faced at the second time point. It was not possible to know at baseline who experienced difficulties or what they were so all participants were invited to participate in the interviews. At the same time, an adequate sample was necessary to explore HNC survivors' experiences after returning to work and how they change over time. Furthermore, stratification of the sample was not used as this was a consecutive sample recruited for the quantitative study. The sample was large enough to allow individual experiences and personal stories to emerge over time and enrich our confined knowledge of this client group.

2.1.3. Procedure

Ethical approval for this study was obtained from the local research ethics committee.

Patients were approached between January 2007 and August 2008. They were recruited from the relevant outpatient clinics of London hospitals. Patients were interviewed face-to-face 4 weeks following completion of their treatment. They were contacted by telephone 12 months post-treatment to arrange a follow-up interview.

2.1.4. Interview schedule

A qualitative approach was used to explore respondents' personal experiences in regards to work. Key themes and concepts were explored and two case studies were identified.

Semi-structured interview schedules were developed through the review of previous research findings and discussion with health psychologists and were offered individually to patients. The structure of the interview was loose and consisted of open-ended questions that defined the areas to be explored. In addition, they were also flexible so as to allow the emergence of issues during the interviews (Table 2).

Table 2: Main interview questions at baseline and follow-up interviews

Baseline interview	Follow-up interview
How do you feel about the prospect of returning to work?	Have there been any barriers in returning to work?
Do you feel that returning to work will be a relatively easy or difficult process?	Have there been any difficulties at work (i.e. with the work environment of the performance of your role) due to the cancer diagnosis or the treatment that you have received?
Do you feel you will be able to carry out all of your duties in your job?	What were the enabling factors in returning/not returning to work?
Have you told your employer that you have cancer? If so, was their response positive or negative, helpful or unhelpful?	What have been the implications of returning/not returning to work?
Before your cancer diagnosis how did you view work, (positive/negative experience)?	Can you think of the advantages or disadvantages?
Do you feel that work is an important aspect in your life?	Are you happy with how your return to work process? Did it go as you had planned?
Do you have any career goals within your current job?	How do you view work now? Has your view changed? Is work enjoyable? Do you see work as important?
Do you have any long-term career goals that you want to achieve?	Do you have any career goals and have you made any steps in achieving them?
Do you think your cancer of the treatment you have received will have any impact on your work or role performance?	What are your main reasons for returning/not returning to work?

The baseline interview focused on the perceptions of returning to work, one's ability to resume their role, cancer's impact on their work along with work values and goals regarding their work and life.

The follow-up interview focused on issues around the process of returning to work, their ability to carry out their duties, perceptions of work along with work values and career-wise of life-wise goals.

Interviews were conducted separately from routine care either over the telephone (n=29 – 16 at baseline and 13 at follow up interview) or in a private room at the hospital (n=50 – 31 at baseline and 19 at follow up interview). Baseline interviews lasted on average 31 minutes (range 21-58 minutes) while follow-up interviews lasted on average 26 minutes (range 23-40 minutes). There were no differences in the length of interview, or depth of the responses, for telephone compared with face-to-face interviews.

2.1.5. Analysis

All interviews were tape-recorded and transcribed verbatim. To maintain anonymity, each participant was assigned a code.

The interviews were analyzed using thematic analysis. This method is one of the most commonly used in qualitative studies and was chosen over others because its approach served better the purpose of this study which was to explore individual experiences in more depth but still following a semi-structured approach. Thematic analysis focuses on identifiable themes and patterns (Benner, 1985; Leininger, 1985), which were anticipated to emerge through the interviews collected for this study.

Contrary to other qualitative techniques such as Discourse analysis (Gee, 2005), or Conversation analysis (Psathas, 1994)), thematic analysis does not

depend on any specialized theory and this renders this technique more accessible. If a Framework analysis (Ritchie and Lewis, 2003) was applied in this project, then it would have allowed comparison across and within cases and this would have enable comparison across the two time points. However, it would have required 79 individual matrices to be produced, one for each interview, and this amount of matrices would be potentially unmanageable. The Interpretative phenomenological analysis (Smith, 2009) is a preferable approach when the sample size is small and the in-depth analysis regards a probing interview about the *meaning* of the different events to the individual. Thus, it was not an appropriate approach for this study because the sample was big and had a different focus on the interview schedule in that questions aimed to identify the experience of returning to work and changes in work and life goals. Also, the questions were not formulated having the interpretative phenomenological analysis in mind. Finally, the Grounded theory (Dey, 1999) was considered unsuitable for this study because the data were already collected whilst the analysis in this approach takes place at the same time with the data collection and ceases when it reaches saturation.

The phases of thematic analysis as identified by Braun and Clarke (2006) were followed in the present study. The first key step was the familiarization of the data in order to ensure an expedited and insightful analysis and this was achieved with repeated perusal of the interviews.

The transcripts were subsequently analyzed by noting relevant units of meaning and creating free nodes using NVivo 8 (QSR International); a computer program that helps with the organization, analysis and visualization of information (Bazeley, 2007). In other words, small chunks of data were coded by being given a name and, if necessary, a brief description.

This coding process was guided by two main rules. The first was to identify data which were related to the interview questions and thus to serve the purpose of this study, and the second to code any chunk of data which emerged within the context of having survived the experience of HNC, even if it was not directly linked to the interview questions. Thus, the coding was dense and took place every time either of the above rules applied.

Below, examples of a participant's responses from the transcribed verbatim of the interview will be used to illustrate how the coding process took place.

At first, the participant's response *"To be honest with you, unless I go there and try I don't know"* when he was asked *"Do you feel you will be able to carry out all of your duties in your job?"* was initially coded as a free node.

Free nodes were then grouped into coherent themes, in that earlier coding was readjusted in the light of experience and as ideas developed. The idea behind this was to achieve the closest possible fit of the coding to the data and dismiss a plethora of idiosyncratic coding.

Using the previous example, the above statement and other similar ones were subsequently grouped into a coherent theme named *"Don't know"*.

Once themes had been identified for each participant coding was once again altered and modified in the light of the full picture of the data. This was achieved by integrating these themes (i.e. substantial sets of coding) across participants to generate a list of super-ordinate themes that captured the participants' common experiences.

For example, the above theme "Don't know" was then put alongside other coherent themes and altogether generated the super-ordinate theme named

"T1 Duties". This theme encapsulated participants' responses a month after their treatment with regard to whether they would be able to carry out their duties upon return to work. This theme was eventually renamed and described as "Ability to perform everyday tasks at work" and was presented in the Sub-themes section.

All stages of the analyses were characterized by a trial-and-error process, in which adjustment was a regular feature. The aim was to reach a phase where each theme was sufficiently and clearly defined to serve analysis and communication of the results.

Subsequently, examples of each theme were identified to illustrate what the analysis had achieved and were presented in Chapter 3, 4 and 5.

The presentation of themes' frequencies across the database was not undertaken within this study for two main reasons. Firstly, because the interview schedule did not use exactly the same questions to each participant as some were providing spontaneous responses to topics that were relevant to them, whereas others not. Therefore, the provision of frequency information would have been misleading. Secondly, the focus of the present study was not based around the numerical indication of incidences and prevalence of each theme in the data but on every emerged theme and its significance for this particular clinical population. In qualitative studies only one occurrence of a "code" (i.e. a piece of data) is necessary to ensure that it becomes part of the analysis and can potentially be as useful as many in understanding the process behind the topic. This is because the aim of qualitative research is not to produce generalised hypothesis statements but is concerned with meaning (Crouch and McKenzie, 2006) and thus frequencies are rarely important for such designs (Polgar and Thomas, 1991).

Finally, inter-rater reliability was used as a credibility check (Elliot, Fischer and Rennie, 1999) throughout the study to ensure robustness in its process. At the beginning of the analysis, both the supervisor and the author of this thesis separately analyzed 15 interviews and met to discuss the identifiable nodes. No differences in their identified nodes emerged. Subsequently, they met regularly to examine whether the coherent themes of the analysis were similar. At the last stage of the analysis, they checked the super-ordinate themes and no disagreements between them across the different themes were emerged.

2.2 PRESENTATION

Chapter 3 introduces the emerging themes from the baseline interviews while Chapter 4 the themes emerged from the follow up interviews only. Usually a paired analysis approach allows changes across time on an individual basis and then trends across the group to emerge. Yet, the aim of this project was to look at the experiences of the group as a whole and not at an individual level. Therefore, a paired analysis between data from T1 and T2 was not used; themes were compared as groups.

One super-ordinate theme "The effect of cancer on HNC survivor's attitude and perception of life" was identified both at T1 and T2 and it is presented in Chapter 5. All respondents were given a pseudonym, which is presented along with their age and occupation.

CHAPTER 3

RESULTS: T1

3.1 EMERGING ISSUES FOUR WEEKS AFTER TREATMENT

Three main themes emerged from HNC survivors' interviews four weeks after their treatment (T1) regarding work and life views: "issues around return to work", "work values" and "goals". These main themes along with a number of sub-themes related to them were explored.

Table 3 summarizes the main themes at baseline. The first column presents the three main themes and the second column the sub-themes that correspond to each main theme. The third column provides examples of the issues that emerged under each sub-theme to illustrate respondents' answers. This format allows the reader to get a quick summary of the emerged themes.

Table 3: Main themes, sub-themes and examples of emerged issues from interviews

Main Theme	Sub-themes	Examples of emerged issues
Issues around return to work - for patients who would return to work in due course - for patients who had already returned to work and for patients who continued working during treatment	**Advice**	None Too early to receive information No need to receive any Decision was left to the patient
	Informed employers	Yes - positive and helpful Yes – negative and unhelpful Did not disclose information
	Main reasons for return to work following treatment or remaining at work during treatment	Bored at home Financial Able to go to work
	The process of returning to work or keep working while in treatment	Easy Difficult
	Ability to perform everyday tasks at work	No problem at all to carry out duties Able to carry out most duties but some physical, cognitive and emotional difficulties present
Respondents' value of work prior to cancer and after	**Positive view of work before cancer**	Nice working environment Good relationships with colleagues Interesting nature of the work Sense of achievement and personal satisfaction
	Negative view of work before cancer	Necessity Physical and/or psychological difficulties
Work- or life-related goals following cancer treatment	**Respondents with work- or life- related goals**	Developing skills & competence Promotion Expansion of private business New role Better life balance and personal development
	Respondents without further work- or life- related goals	Content with their current job status Lost interested in their job Avoidant of physical or psychological challenges Close to retirement age Changed lifestyle to be present-oriented Content with their current life status

3.1.1. Issues around return to work

At T1, most respondents would return to work in due course but one third of them had either returned to work already or continued working during treatment. The identified subthemes in regards to "issues around return to work" were explored within these two different "groups" and were the following: advice regarding return to work, whether they informed or not their employers, their perceptions and current pressures in regards to return to work or the main reason they returned to employment for those respondents who were already working at T1, how the latter found the process and their duties when returned to work and how those who were

due to return believe that the process might be and how they will find their duties.

3.1.1.1. Advice

Many respondents who were to return to work in due course did not receive any information in regards to this matter nor about how to make the transition back to work. It is possible that this happened because it was too early to provide patients with such information.

> *"No they [the consultants] didn't, to be honest. It happened so quick we didn't really discuss it." (Helen, 46, Mortgage advisor)*

A number of respondents felt that there was no need to receive such information either because this issue was not relevant so far although unanswered questions had started to emerge or they did not think this information would be helpful to them as they felt self-reliant and confident in their judgment.

> *"I haven't needed to know anything so far, and I haven't been given any information from my employer or from the hospital or anything, but I am starting to now have questions."(John, 22, Administrator)*

> *"No. I've got all the Richard Dimbleby cancer booklets and all that what they give me up St. Thomas's. I've got all them, I've read all them. I think it's one of them things where you don't actually need no one, well I don't I don't need actually need no one to tell me when I'll be fit for work, I think I'll know myself." (Ed, 58, Lorry unloader)*

The decision in regards to return to work was left to some respondents to judge for themselves either without any further information or with simply

some encouragement or acquiescence by their medical or other health care professionals. On some occasions however, this was not particularly helpful as patients felt that they were not ready to return to work due to concerns about whether they were fit enough or able to regain their fitness post-treatment.

> *"Yes, the doctor just said when I felt up to it. Errm, she left it with me." (Robin, 55, Electronic technician)*

> *"The first person that ever asked actually, not Dr. … not the oncology team haven't asked, but the ENT specialist […] he said the treatment worked. But I'm still sick, I'm sick from the treatment rather than the cancer, which couldn't be avoided." (Anna, 46, nurse)*

Only a few respondents who had already returned to work or continued working during treatment received advice either from their GP or after they sought information from them.

> *"So it was really just advice from my colleagues really and my GP." (Bob, 56, Post room assistant)*

> *"When, before the treatment started, […] I asked at the time sort of, as many questions that I thought might be important. And got answers to everything, and I just sort of worked it off from there really, you know." (Tim, 55, Carpenter)*

Most respondents however, did not receive relevant information because they did not feel they needed any, or because the decision was left to them or because they just decided themselves what to do.

"No I just asked if it was ok for me to go if I could go back to work and the doctor says well it was up to me. If I felt I was fit enough to go back to work then I could go back to work. They left the decision up to me." (Matt, 56, Head builder)

"Don't think I took any advice, I went on gut instinct." (Anton, 61, Security officer)

3.1.1.2. Informed employers

Most respondents who would return to work in due course had informed their employers about their condition. They felt that the experience of disclosing this information was in general positive and helpful as the employers eased them back to work through a phased return. This means they tried to accommodate their employees' needs; sick pay while away on treatment, being flexible in regards to when they should return to work, with their working hours or with taking time off, facilitating a phased return to work and putting them in contact with the relevant welfare departments. Many respondents also reported that their employers' kept in touch with them and were caring about their wellbeing.

"Mind you the firm's really good. I've been up to see them and they said take your time, the job's here. They said they would even take me back part time, until I get back to normal." (Emmanuel, 61, Warehouse packer)

"[…] my boss has said to me […] I could actually go back for three days the first week if I want to or whatever. […] He just said to me […] just let me know how you are, how you're getting on. Don't worry about nothing, if you need any meat sent home just phone me […] it'll be sent home" and all that. "Your wages don't worry about." (Ed, 58, Lorry unloader)

Some respondents would have preferred greater interaction with their employers and to receive more information from them (e.g. in regards to sick pay). They felt disappointed about the lack of interest and contact despite the fact that they informed them about their diagnosis. They found their employer's response unhelpful and perceived this experience as negative.

> *"I just literally told them that I'd been diagnosed with oral cancer, and that I was going into and have radiotherapy. They haven't really asked, they haven't. I think that would've been an appropriate thing to do. I wouldn't have found it intrusive at all. Just to keep up the contact really. So I expected that anyway, they're not very good like that. You wouldn't think that they're a public service basically, you wouldn't think that. But never mind…" (John, 22, Administrator)*

> *"[…] nobody's really bothered to… I've done all the chasing about getting people for a home visit and stuff […] And especially when there's information that you need to know. It's from calling about my sick pay and I've been calling in, I've been told that it's against company policy to find out about your sick pay, how long I've got. So because of that I didn't really know when it finished. But the thing about it is that should've been managed. Because nobody's told me that I won't get my full pay. Basically I can get that information from a home visit, but because they haven't done the home visit I don't know the information." (Sonia, 34, Assistant manager)*

Only few respondents decided not to disclose their condition to their employers. The main reason for non-disclosure was to avoid other people's preconceptions about cancer (i.e. beliefs about how it could impact their ability to work) and potential consequences because of these beliefs. This

decision could be directly linked to the stigma around cancer including patient's perceptions of stigma.

> *"It hasn't been an issue, I haven't told … I work for a variety of people, obviously […] I haven't had to tell anybody I work for and so I haven't, because it hasn't affected my work. […] I would probably not have told people I work for, because one worries that they think 'oh cancer, therefore, she's terribly ill, therefore, she may not be reliable or about to die on us before she finishes this book' or something like that. I didn't tell the people I work for because I wasn't sure what their preconceptions were, and I didn't want them not to send me work because they thought I was ill and couldn't do it when I wasn't ill and could do it." (Alice, 51, Sign language interpreter)*

> *"Well there's no need to […] because immediately people start dismissing you." (Carl, 52, Architect)*

Some respondents who were already back at work or did not cease working during treatment found their employers helpful and understanding towards their needs. They were given allowances in regards to time off and worked around the situation flexibly and in partnership. For one respondent the response from the employer went even beyond statutory obligations and was supportive on a personal level.

> *"[…] at times I've been actively encouraged not to come in […] at the same time if I phone and go, I don't want to come in today, it's like fine, what needs doing we'll get it done. […] It was my line manager's idea [to hire a freelance person for cover]. I was able to say look, you know, if I was sort of feeling a bit - I'd just sort of say can you crack on with this I'm going home, they'd say no problem, yeah. […] all my terms and conditions have remained*

the same." (Lee, 54, Press officer)

"I'm escorted from work to home. They won't let me … I mean the job's only over the road it ain't even like five minutes away. But they get someone to run me home if I … it ain't as if I've got to walk anywhere. I'd give them 100 out of 100 … for the system they're using. No doubt about it, because they was running me to my appointments and all beforehand. That was my area officer, he was taking me up there … I can't fault anything they've done. They've done everything" (Steven, 55, Grounds maintenance)

However, there were some respondents whose experience disclosing their situation to the employers was negative and unhelpful.

Respondents found their employers not discreet and inflexible in regards to time off in order to attend hospital appointments. In consequence, this caused strong emotional responses.

"I said to my boss, "If this treatment is partially or completely successful I will be coming back but in the meantime I would like you to be very, very discreet, […] and presumably the personnel director had to know, and he told his PA, and she told her best friend, and der, der, der, der... and it goes down the line.(Anton, 61, Security officer)

In addition, some respondents found their employer's inconsiderate in regards to their condition and that they failed to understand the impact of treatment (i.e. its disabled and long-lasting side-effects) regardless whether the cancer is still present or not. As a consequence of this lack of understanding, some employers removed adjustments initially put in place for support.

"[…] she is slightly ambivalent about this lap top thing, and she said […] you'll be assessed sort of every 6 weeks or so, whether you still need it, and she said, but if you have this CT scan next week and you are all clear, you might not get it in the first place, and I am thinking, hang on, it wasn't the cancer that was causing me to be ill, that never caused me to be ill, it was the treatment. But this is slightly worrying that […] if they tell me it's gone, that I am suddenly not ill." (Terry, 46, Police advisor)

3.1.1.3. Main reasons for return to work following treatment or remain to work during treatment

Most respondents' main reason for returning to work following their treatment and recovery was to get back into the working routine and avoid feeling bored at home.

"Oh I'm looking forward to it. Yes, yes I'm fed up with being at home all the time." (Mark, 57, Maintenance manager)

"It's something that I want to do. Because, you know, I'm used to working. I get very bored if I was at home, my girls are all at school. I'm looking forward to it. So part of me, the reason I'm going back, is because I want to break that pattern of not working. I had a great job and it's something I want to go back to." (Jack, 46, Learning support worker)

For other respondents' however, the main reason was financial as they had commitments to meet and this was a pressure for them to return to work as soon as their treatment was concluded.

"I mean I'm self employed so what it is, if I don't go to work I don't earn any money[…]" (Daniel, 60, Taxi driver)

"I have four children as well so I've had to work really because I have to." (Helen, 46, Mortgage advisor)

The main reason for those respondents who had already returned to work or kept working during treatment was that they felt able to continue work.

"Because I don't feel unwell … I had no side effects of those. As far as I'm concerned I'm not ill. And it's not really affecting my job." (Nick, 56, Civil servant)

Others felt that they did not want to stay at home idle-handed and they preferred to be in a working environment.

"They all kept saying me I was going back too early. But I said that's the way I am, I cannot sit indoors and do nothing, it's just making me ill thinking like sitting here not being able to do anything." (Steven, 55, Grounds maintenance)

Some respondents had to keep working during treatment because of financial pressures.

"[…] financially, you know. I've been self employed, I mean I don't get anything if I am off […] obviously not having radiation before, I had no idea how it would affect me, and I thought, well if I can, I am going to do some kind of work in the period you know." (Tim, 55, Carpenter)

3.1.1.4. The process of returning to work or keep working while in treatment

A number of respondents anticipated that overall the process of returning to work in the future would be easy and they will be able to cope. They predicted that their current difficulties would be controlled or they will find

a way around them or that any current concerns would be dissolved in good time.

> *"I mean it'll be easy as far as, to be quite truthful I suppose it's a bit like your job in an hospital, you can be away there forever and a day but as soon as you go back you're only there half hour and it's like you've never been away. […] within an hour or so it'll be like this three months/four months had never happened." (Ed, 58, Lorry unloader)*

> *"Yes obviously I do expect to be tired when I go back, because not working for eight or nine weeks… but they are well aware of that so I haven't got any problems. Like if I turn around and say "I'm tired I want to go home" I know that will be fine." (Helen, 46, Mortgage advisor)*

Many respondents anticipated difficulties that they may encounter upon return to their work. These difficulties were related to the nature of their work, their workload, the fact that they have been off work for a while, lack of confidence, tiredness, physical problems, dealing with other peoples' questions towards their condition and negotiating the conditions regarding their return to work with employers.

> *"I'm worried about when I go back also catching up. Because, obviously, when somebody else is doing your work they don't always do it the way you do it and …… there's always something that you have to pick up. And I'm really, really worried about things like that." (Martha, 43, Occupational therapist)*

> *"I'm not sure. I'm sure the tiredness will kick in […] I think it's going to be quite tough. I have ups and downs. I have two days when I feel like superman, and then I have a day when I feel rubbish." (Paul, 40, Brooker)*

Some respondents could not predict how their return to work would be until they actually attempted to go back. This was due to their physical difficulties at the time and concerns about whether they will be fit enough to work.

> *"I'm still getting over what I've been through and I tend to have a sleep in the afternoon. Which obviously working I won't be able to do. So once I start I'm going to see how I get on. So I'm just going to take it as it comes." (Patrick, 45, Carpenter)*

On the other hand, many respondents who either continued working during treatment or had already return to work found in general the process easy and others' people response towards them positive.

> *"I've worked all the way through yeah. It's been fine, it's been easy […] I haven't had any work issues, I've just gone as normal." (Harry, 59, Company director)*

> *"No [difficulties getting back to work]. Yeah everybody was pleased to see me. It was quite good really. I was a little apprehensive first of all, I didn't know how people were going to react, but in fact everybody was fine." (Harry, 59, Company director)*

There were however some respondents who encounter difficulties while they kept working during treatment or shortly after they returned to work. These difficulties concerned mainly other peoples' responses towards them, difficulties with traveling to and from work and feeling tired.

"I have popped in three or four times over the last couple of weeks. And I've been chatting away with the staff. The only trouble is possibly is just explaining people's… when I went in last time I bumped into Dr. Jenny and she said, "I haven't seen you for months, where've you been"? So I told her and she was shocked. I'm probably going to get a lot of that the first few… first week or so I'm back at work." (Jerome, 55, Domestic services manager and NVQ assessor)

3.1.1.5. Ability to perform everyday tasks at work

Few respondents who were to return to work in due course predicted that they would not face any difficulties and they would be able to carry out all tasks.

"What it is I don't think there's any because I've still got the use of my arms and my legs and my eyes and all those type of things, the answer is to that question is no." (Martha, 43, Occupational therapist)

Yet, a greater number of respondents reported that although they would be able to carry out most tasks, they anticipated facing physical, cognitive or emotional difficulties.

In regards to the physical difficulties, most respondents referred to communication or somatic tiredness. Some of them, however, were already contemplating ways to work around this.

"No [duties not able to do]. I'm pretty open with everybody about it; they all know I've had cancer. I've had about a third of my tongue removed, they know that. And they've all been supportive and accept it, there's no problem. So if my speech is a bit… I can always email them." (Jerome, 55, Domestic services manager and NVQ assessor)

Quite few respondents focused on possible cognitive challenges that they might face upon return to work regarding slower information processing speed, memory difficulties and concentration.

> *"Well I've been at home resting and, you know, I am walking but I think… what I find, I am slightly worried about is that I think my concentration isn't as good as it was. This marking and the tutorials required huge amounts of concentration. So that's a slight worry." (Monika, 59, Teacher trainer)*

One respondent referred to emotional difficulties hindering his return to work.

> *"I work as a pianist […] I was feeling very depressed. I couldn't do what I was doing as a musician. And my technique and everything was failing me. And it wasn't possible to perform to a high standard [...]." (Luke, 32, Musician)*

On the other hand, most of the respondents who had either already returned to work or did not stop working during treatment were back to their normal tasks and duties without any specific difficulties.

> *"But, I'm doing now exactly what I did before my condition was diagnosed and I'm, I'm very happy to be able to do that.[…] there was no difference at all, my condition made... had no impact at all on what I was doing as a job, so my condition didn't, didn't affect it either way." (Anton, 61, Security officer)*

3.1.2. Respondents' value of work prior to cancer and after

Respondents talked about the way they viewed their work before their diagnosis as well as whether this view changed or remained the same following their diagnosis.

3.1.2.1. Positive view of work before cancer

The largest proportion of the respondents reported that their view of work was positive before their diagnosis. Many of them emphasized the importance of a nice working environment and good relationships with colleagues as contributing factors for their positive view of work.

> *"I really like where I am […] where I work is very nice, nice settings, nice people and I really enjoyed it and that's probably why I wanted to continue." (Susan, 47, HR manager)*

> *"[…] I like what I do and like the people I work with and the students." (Tom, 44 University lecturer)*

A number of respondents also focused on the interesting nature of the work which led to a personal sense of achievement and satisfaction that was positively reinforcing them.

> *"Yeah. I enjoy doing that, enjoy meeting people and I enjoy being active and doing it. […] I go out in the morning and be happy to be going out and going to work as opposed to having to go to work and not be enjoying it." (Troy, 56, Telephone engineer)*

3.1.2.2. Negative view of work before cancer

Fewer respondents reported that they were holding a negative view on their work before they were diagnosed. Many of them noted that work was

something they had to do in order to gain money and be able to live while they did not particularly enjoy doing it.

> *"Well it was a necessity it wasn't something that really really excited me [… So I'm not really concerned about the job itself." (Michael, 56, Technician)*

> *"[…] I didn't enjoy my job […] it wasn't a high priority. I need to work for financial reasons but if I had to choose… you know… (John, 22, Administrator)*

Quite few of them mentioned that their view of work before cancer had started to become negative, mainly because of the nature of the work which was causing them physical and/or emotional difficulties.

> *"I must admit I was feeling that it was beginning to get too much for me. I must admit it was becoming physically exhausting. It's physically and emotionally and psychologically exhausting, I must admit. Before I was diagnosed." (Martha, 43, Occupational therapist)*

3.1.3. Work- or life-related goals following cancer treatment

Many respondents reported that they had work-related or life-related goals which they wished to achieve. Respondents discussed about the aims they aspired to reach following their cancer treatment.

3.1.3.1. Respondents with work- or life- related goals

Quite few wanted to keep developing their knowledge within their current work position. They aspired to improve expanding their skills and their competence.

> *"Yes I mean certainly there are things that I want to do and things I want to develop because part of the job is always improving what you're doing and*

what you know and these sorts of things, which is one of the fun things." (Tom, 44 University lecturer)

There were few respondents who were interested in getting a promotion. They had preserved their ambition in going forward and reach for higher positions within their current working environment.

"I'm hoping I may want to go up to perhaps one more level which is, I think will be in my grasp. You know I'm not going to go overboard though to get promotion I'm just going to take it bit more steady you know." (Adam, 55, Civil servant)

A respondent who owned his own company wanted to expand his private business.

"[…] I hope to pitch […] and then we can afford to expand." (Carl, 52, Architect)

Many were interested in attempting a distinct role within their profession; some wanted to do something completely different and few wanted a change but were not sure exactly of what sort.

"What I would like to do but I don't know if I'm going to be able to, is take the retirement and then become a driving instructor." (Blake, 61, Teacher secondary)

"At the moment yeah [go back to the old job]. I mean in time I would like to change. I will do [look for something in the future]. Probably completely different actually." (Sonia, 34, Assistant manager)

In regards to life goals, quite few respondents expressed the wish to achieve a better balance in their life and work on a personal development level.

> *"[…] I feel I can spend more time with my daughter as well. And I can get more of a balance, and actually doing what I want to do, and spending time at home." (John, 22, Administrator)*

Many referred to hobbies or dreams they wanted to pursue following their recovery from cancer and its treatment. These hobbies and dreams were related to trips or activities which they wished to enrich their lives with.

> *"[…] all my ambitions, are all about running […[and coaching, that's what I want to do, but if I had the choice, and enough money, I would give up work tomorrow morning, if I won the lottery, and concentrate on those two things, and I would be as happy as Larry then." (Terry, 46, Police advisor)*

> *"I'm going to give myself two or three months off. But I've got the book on the 'Over 50s Activities'. I intend to enroll in the swimming club and the bowling, indoor bowling club, plus I'm going to go once a week to tennis. I'm going to have two or three bits and pieces so that I'm not sitting at home doing nothing." (Harry, 59, Company director)*

3.1.3.2. Respondents without further work- or life- related goals

However, a slightly higher number of respondents did not report any particular work goals. Many of them were content with their status at the time and did not want to proceed with any further development nor did they want to explore any new career paths.

> *"No I've always wanted to be a teacher there's nothing like it." (Emma, 56, Infant teacher)*

Quite few of them either never had any goals at work or had already achieved their goals before their diagnosis.

> *"I feel I've achieved a lot in my career before having children." (Mark, 57, Maintenance manager)*

Some were not prepared to take on any further physical or psychological challenges. They were content in pursuing their work duties as they were prior to cancer without adding any further ones which would require of them to work longer or experience more stress.

> *"No, I'm quite happy as I am. I started on the firm as a qualified carpenter, he [my friend] came on there as an unqualified carpenter, but because his father owned the company he sent him back to college […] so he is now my boss, whereas he used to be my trainee as such. The roles have reversed but I'd rather he has the hassle that he has now, I get on and do the work and he gets all the phone calls and has to do all the running about. I'd rather just get on and do my work." (Patrick, 45, Carpenter)*

Some others thought that their age was acting as a check on them.

> *"No got a bit too old for that. No, to be quite honest I was totally fulfilled." (Anna, 46, nurse)*

> *"Not really. Promotion and that sort of thing there's not a lot of promotion […] No I don't, the answer to that is no I don't basically. "[…] at my age the answer to that question is there's no point." (Nick, 56, Civil servant)*

Finally, in regards to life goals, few respondents reported that they were

either content with their current situation or they did not feel as if they were missing something out thus had no aspiration to achieve any.

> *"No. I've got a happy life at home- content got a house, and a mortgage and all the rest of it, fairly content. There's nothing outside which I want to do particularly, no." (Adam, 55, Civil servant)*

CHAPTER 4

RESULTS: T2

4.1 EMERGING ISSUES 12 MONTHS AFTER FIRST INTERVIEW

Five main themes emerged from HNC survivors' interviews 12 months (T2) after their first interview (T1): "problems upon return to work", "employers' response towards those who returned to work", "respondents' value of work and work- or life-related goals following cancer treatment", "proposed improvements for the care of HNC survivors" and "advice to other HNC survivors". These main themes along with sub-themes were explored.

Table 4 summarizes the main themes that emerged at 12 months follow-up solely. The first column presents the five main themes and the second column the sub-themes that correspond to each main theme. The third column provides examples of the issues that emerged under each sub-theme to illustrate respondents' answers.

Table 4: Main themes, sub-themes and examples of emerged issues from interviews

Main Theme	Sub-themes	Examples of emerged issues
Problems upon return to work	Respondents who faced mild or moderate difficulties upon return to work	Physical Cognitive Conditions at work
	Respondents who did not face any difficulties upon return to work	None
Employers' response towards HNC survivors who returned to work	Positive and helpful response from the employers	Allowances e.g. time off Remain on salary
	Negative and unhelpful response from the employers	Inflexible
Respondents' value of work and work- or life-related goals following cancer treatment	Respondents who value work negatively after cancer	Work not as important anymore
	Respondents with no further career goals	Carry on as usual
	The role that work fulfills in respondents' life	Work even more important now
	Respondents with further career goals	Career change
	Respondents with further life goals	Buy a house
Proposed improvements for the care of HNC survivors		Emotional and financial support Further information on legal rights None necessary
Advice to other HNC survivors		Demystify cancer by finding out about cancer Stay positive Return to work

4.1.1. Problems upon return to work

Most respondents reported either mild or moderate difficulties upon return to work but few of them did not face any when began working again.

4.1.1.1. Respondents who faced mild or moderate difficulties upon return to work

For some of them, difficulties did not last for too long as they resolved themselves with time.

> *"[…] it was okay it really was, I thought I was bound to be dozing off in the middle of the afternoon, but no … the only side effect was not really losing the voice, but with a sore throat which was expected and you're husky, therefore, I couldn't go to court because my job going to court. And I*

couldn't present cases to the judge because they couldn't hear me. That went on for about three weeks. Apart from that nothing." (Nick, 56, Civil servant)

Most of the respondents however, encountered different difficulties upon their return to work. Many reported tiredness as the main problem but often they were given allowances from their employees in order to resume their duties at their own pace while remain on full salary and avoid any further inconvenience. The employer's flexibility was important to them at the time as it assisted their gradual return to work.

"Yeah I did [feel tired]. The problem I was having was I wasn't eating. But what I did is I came in, I suppose for a couple of weeks my manager said you should reduce your hours, not to not get paid, I got paid full pay, but she said come in at ten and go at four." (Susan, 47, HR manager)

Some respondents found the conditions at work inconvenient due to the nature of the job (e.g. overloaded demands) as well as difficulties with concentration and memory and learning new things which led to mistakes at work. Dealing with work issues while still unfit seemed to have hindered recovery. Yet, for few of them return to work was unavoidable due to financial pressures.

"I'm really behind now and completely overwhelmed and I think I went, you know, I sort of, jumped in at the deep end, definitely. You know, I only finished my treatment probably, like, four months before and I was still quite ill when I started so I'm sort of playing catch up with my body and now I'm playing catch up with the work as well." (John, 22, Administrator)

"I'm not doing it as good as what I used to. Sometimes because I still get pretty exhausted I tend to put things off. I just go at my own pace and when

it's not done I just work overtime. […]That's very difficult [keeping my mind on work] yeah. […] That is a bit of a problem [learn new things]."(Michael, 56, Technician)

"There's a machine standing there, it's a computer controlled machine, and it's actually a very logical thing to learn, and I'd love to learn it but I just don't have the capacity to. […] So to learn something new is difficult for me now at this point. I think purely because my memory just can't … If I really have to remember something I have to actually write it down and visualise it and then I can actually remember it." (Michael, 56, Technician)

"[I make] terrible mistakes [at work]. Couldn't count. […]But I'd think, hold on I've just made these things. I was like living in another world." (Michael, 56, Technician)

Many respondents experienced various physical difficulties such as problems with movements and posture, dry mouth and difficulties in swallowing, problems with their voice and talking. Some attempted to work around these difficulties by making necessary adaptations (e.g. change posture, use PowerPoint instead of talking. However, this was not possible or sufficient to everybody due to their work requirements (e.g. speaking with costumers, teaching a class with 30 children).

"[…] I was really stiff then like with my arm and that, I couldn't even turn my head round or nothing when I first went back yeah, but it gets better […] with certain things I have to kneel down more, sort of bend over you just do it different the way you feel comfortable. Yeah I've adapted. I know I haven't got the strength at the moment. There's other ways you get round it." (Mark, 57, Maintenance manager)

"I'm still having problems projecting my voice in an authoritarian way. You know, when you've got 30 children. I mean, sometimes they can be lovely and other times they can be ghastly" (Emma, 56, Infant teacher)

Few respondents found difficult to deal with other people inquires after they disclosed their condition to them.

"Yeah that got on my nerves a bit, people would ask how I was, and they wanted to go into the ins and outs you think … it's all right telling one person but you do it every other you think, I've had enough." (Mark, 57, Maintenance manager)

4.1.1.2. Respondents who did not face any difficulties upon return to work

Quite few respondents reported that they did not face any difficulties upon return to work. They emphasized the fact that they did not experience any physical or psychological symptoms at the time which could have impact their work.

"No, I didn't miss a day's work before and I haven't missed a day's work since. It's all as if it's a strange interlude in your life and it didn't really happen, it could've been a dream and you'd never know any different. […] But there were no symptoms no lasting effects that changed my life in any way whatsoever. It was, as I say, it was very strange and fantastic." (Sam, 54, Taxi driver)

"I think I'm better, almost full, yeah ninety-five percent full health, if you're physically fit, mentally fit, forget about it and, you know, get on with work." (Lee, 54, Press officer)

Some respondents described how support from their colleagues was crucial

to them as it gave them the opportunity to ease back into work and resume their duties.

> *"Yeah I was fine no problem, a lot of the fellows I work with sort of eased me back into it gently you know don't do this and don't do that […] so they help me out quite a lot yeah […] yeah no problems. […] I'm doing exactly the same job." (Ed, 58, Lorry unloader)*

4.1.2. Employers' response towards HNC survivors who returned to work

The experience of respondents who returned to work following successful treatment differed in that most of them found their employers' response positive and helpful but few of them found it negative and unhelpful.

4.1.2.1. Positive and helpful response from the employers

Most respondents received a supportive response from their employers. The latter supported their employees by making allowances with time off and lowering their expectations in regards to performance.

> *"They've been great. Yes, I asked the doctor […] if I could go back straight after the radiotherapy and they said, well 'give it another couple of weeks'. I told my work and they were good as gold with it and said 'it's fine'." (Matt, 56, Head builder)*

> *"Perfect no problems. Yes – they were quite understanding. Very very very supportive […] Between January and March I couldn't do 100% of what I used to do. I was 80%." (Victor, 45, Legal advisor)*

Some respondents continued to receive their salary while off work. This support was very significant to them at the time when they were dealing with their illness and saved them from financial worries.

"Yeah [my employers] they've been excellent yeah. I'm very lucky with my employer in that we get six months' full pay if we're off sick, and of course I didn't need it, even half of that. But for that reason I was okay financially and everything […] they were happy to give me all the help I needed really." (Ben, 59, Foreman for scaffolding)

One respondent was pleased with the way their employer dealt with the disclosure of the condition.

"I have to say that school were just totally brilliant about what they told people because it was a surprise and shock and how they told people and how the Head handled it so everybody knew exactly." (Maria, 60, Teacher head of sixth form)

4.1.2.2. Negative and unhelpful response from the employers

However, few respondents' experience was completely different, as they found their employers inflexible and thus neither supportive nor accommodating towards their needs. Thus, their employers' response added further turmoil in their life as they felt they had to find other ways to work around it and this caused them further difficulties.

"The only thing that I have deemed it necessary to do is basically not tell my employer when I need to go into these appointments. I'm fortunate enough that I live and I work within five minutes of St. Thomas's, so I can basically just shoot across, and then come back before I'm missed. Because I'm met with well I guess you could say a misunderstanding masquerading as hostility. So a lot of it's just basically not very sympathetic in essence. It's like with a lot of things there's an initial period of sympathy while you'll undergoing treatment and reoccurrence. So it's just I mean basically I'd

have to go cap in hand and beg for a favour every time I needed to go." (Liam, 28, Electrician)

4.1.3. Respondents' value of work and work- or life-related goals following cancer treatment

The way most respondents valued work changed following their experience with cancer.

4.1.3.1. Respondents who value work negatively after cancer

Quite few respondents reported that work had a predominant role prior to cancer but this was not the case any more.

"No, my views have changed somewhat. Everything was work before, you know, I was mad keen and I didn't exactly jump out of bed raring to go and it was a major part of my life whereas now I couldn't really care less." (Sonia, 34, Assistant manager)

Other respondents said that work is not as important to them as it used to be and they worry less about it now than they used to prior to cancer.

"Yeah, [work] it's not really important, it's not life and death that I'm you know, having my chance to find. Things like that do not worry me as much as maybe they would've a year ago. I don't, you know, I don't feel, that's not what my real anxiety, you know when I get upset, so long as I'm not dying, you know, it's not the end of the world." (John, 22, Administrator)

Many respondents stressed that their priorities changed following cancer and that they are keener now to focus on family and improve their lifestyle.

"[…] in the past I've found myself committing to things that really have been quite hard, and I'm never going to let that happen again. Because I

realised what's important. You know spend time with one's husband and one's family and that sort of thing. So that's certainly something so I think I'd come to that conclusion anyway. As you get older you think, no never again and I want to do what I want to do really." (Monika, 59, Teacher trainer)

4.1.3.2. Respondents with no further career goals

In regards to career goals or ambitions most respondents mentioned that they were content in their current working status and wanted to simply carry on as they were. This was an overlapping theme across the two timepoints as most respondents in T1 also reported that they were fulfilled in their current position and status.

Some respondents explained that this was due to the fact that they were not prepared to take on any further stress in their working life

"Yeah there's no [goals] I'm not … I used to be ambitious, but I'm not ambitious anymore. I'm not seeking promotion or anything like that now, although the opportunity's probably still there, but I'm not … I don't think it's important to me any more not to take on extra work or extra pressures, if you like. I'm just happy just ticking over what I'm doing."(Ben, 59, Foreman for scaffolding)

Other respondents pointed out that their lack of goals and their wish to just carry on as normal with their work was due to the consequences from having had cancer.

"I might've had [goals] before but I don't now. I would've been more ambitious about just becoming more and more specialised, but I don't want

to do that now. I just take each day as it comes. And you can't be ambitious if you're tired anyway." (Anna, 46, nurse)

"I'm happy in the job I'm in. […] You still like, because it's still raw, and you've still got a lot of scar tissue in the throat and that you know most probably a lot of other people have got scar tissue elsewhere, you still need your rest." (Erika, 47, Sales operator)

4.1.3.3. The role that work fulfills in respondents' life

Interestingly, few respondents reported that following cancer the way they valued work changed in a different way in that they began appreciate more the fact that they can still work.

"I've never liked working though. Like most people I go to work so you're earning money but I appreciate now that I can go. When I couldn't go I thought I was never going to go back to work. I think I appreciate it more. It's still there and I don't mind going in so much because I used to always hate Mondays, but now it … I'll get out the house now." (Mark, 57, Maintenance manager)

Some respondents however, still valued work highly even after their experience with cancer. They reported that they find work equally enjoyable and important as prior to cancer.

For few of them the reason was purely on financial and practical grounds in that work is giving them something to be occupied with.

"Well [work is important] financially and something to do, you know." (Tim, 55, Carpenter)

For others, work was still important for social reasons in that they valued friendships formed in the working environment.

> *"Work is very important to me. It keeps my mind balanced; it stops me from thinking, friendship with friends in there." (Erika, 47, Sales operator)*

> *"I don't know what I do if I wasn't going to go to work ((laughs)). I think it's very socially important and they're a big supportive group." (Anna, 46, nurse)*

Some respondents reported that not only work is still valuable to them but they felt even more strongly about work now.

> *"No it's made me even more want to get back to work. It's not had a negative effect it's had the opposite." (Jessica, 52, Veterinary nursing assistant)*

4.1.3.4. Respondents with further career goals

In regards to career goals, some respondents mentioned that they aspired to have a career change and try something

> *"Erm it was something that was an ambition of mine to work as a therapist so erm partly because I couldn't rely on …income from being a musician as well […] Yeah so I've got a reliable stable income so if I can combine that with working as a therapist, I'll have much more chance of having a secure and better income." (Luke, 32, Musician)*

> *"I'm looking to get a settlement out of the company that I was working for and I'm looking to set up something on my own" (Sonia, 34, Assistant manager)*

4.1.3.5. Respondents with further life goals

Regarding life goals few respondents reported that they are currently making plans for the future. They aspired to move to a new country or buy a house and have a holiday.

> *"Yeah. Right now my plans are to go to Thailand. It's a lovely place. … I am building a house in Thailand, I never ever thought I would build a house. I'm busy now at the moment doing it. Yeah. And I'm going to retire there and I'm going to build a boat as well. […] So this [cancer] has kick started me into doing both those things." (Michael, 56, Technician)*

> *"Well, we were planning to move, however, no we are still thinking, you know, we're still looking to wait until the housing market sorts itself out a bit. But no, we're still planning to move, we're planning, we've already got holidays planned, yeah, yeah, you know, so we're looking forward to the future, yeah." (Lee, 54, Press officer)*

4.1.4. Proposed improvements for the care of HNC survivors

Most of the respondents suggested that there is still space for improvements regarding the care of HNC patients. The suggested changes concerned the need for further support on an emotional and financial level, more flexibility within the NHS system and finally the importance of more information in regards to different issues around their circumstances.

Few respondents pointed out the psychological scars after the operation and indicated that they would welcome more support afterwards in the form of counseling. This is especially important in the context of them being vulnerable and weak after treatment in order to look for such services themselves.

"[…] there's the emotion there is you know the state of mind after such a big operation. So really there could be more help with that, in sort of hospitals as well and that is something you feel or at least give you advice on where to go and get that help as well. Lots of services around that have erm low cost or even free counseling and maybe people don't know or maybe people haven't actually got the strength to erm research this and find out where it is in their area so they can go to." (Luke, 32, Musician)

Some respondents emphasized the need to receive financial support or benefits. This is especially crucial in the context of them not being able to work for a period of time and having to keep up with all their other responsibilities. They also indicated the need of having someone to assist them with the applying process given it is a daunting procedure and they are particularly vulnerable by that time.

"You don't get it [financial support] with cancer patients do you … you don't get that. If you struck down with … or you have a mental breakdown then you can get all these benefits, or if you're an alcoholic and that you get all these benefits or how they get it I don't know. And yet people that have got cancer for no sort of like … some people have just got cancer because they don't even know they've got it they don't get no help." (Erika, 47, Sales operator)

Quite few respondents discussed why it would be more helpful if NHS system was more flexible in regards to appointments (e.g. many appointments offered at different dates). They pointed out how this can negatively affect their attempt to keep their job and meet other commitments such as their children's needs which adds further turmoil to their life. They perceived this as an inconsistency in the messages they receive from the professionals in that on one hand the system advices them to try and keep a

work/life balance and on the other hand it is not flexible enough to help them achieve this. Additionally, this can have an extra financial cost to them which although they acknowledged that money can be claimed back, they pointed out that this is not necessarily beneficial to anyone. Finally, they pointed out that the system's holistic approach should be enriched by closer liaisons and communication between the professionals and a coordinator who can orchestrate their care.

> *"[…] whilst the NHS has been absolutely amazing, […] they do tend to forget that you might work as well. So, I know it's difficult. But clinic hours, all that sort of thing, are not geared up……to people who do need to work […] I don't know the way forward on that,…but there is an element of 'well you fit in with us' […] I think often the NHS think, 'well, tough, we're more important'. […] I think that sometimes, because they talk about, you know, holistic approach, so that you know, the speech therapist the dieticians and everybody else sat round and discussed my case. But they don't seem to liaise with each other.So what would be really useful in a way is if you had one person who……ran if you like…coordinated it all." (Jack, 46, Learning support worker)*

Some respondents reported that there was need for HR to improve its services and commitment to its role. They pointed out that HR should become more informed and competent in dealing with people in such condition in order not to have unrealistic expectations of them.

> *"Everything. They could have done everything differently. Well, human resources for a start, they've got no idea. They didn't keep an eye on what I was doing; they didn't have regular meetings with me. It went wrong from the start with them wanting me to go back full time. Them overlooking an*

insurance policy that I was entitled to. I think the law thing is quite an issue." (Sonia, 34, Assistant manager)

Many respondents stressed the importance of receiving further information in regards to possible consequences including physical, emotional and financial along with support available to them and information regarding their return to work. Their reported that health care professionals were too positive when providing information and they mentioned that they would like to have more realistic debrief in regards to how difficult things could be.

"No and I think even medical professionals, sort of, gloss over what the consequences can be and I think that needs to be addressed a lot more. I think you need be warned, 'this is the worst case scenario but it's unlikely that it'll happen' […] There needs to be a lot more information about the consequences and what, you know, the really negative things are rather than 'you'll be fine', and 'you just need to get through the first year' and you know 'five years' and it's not like that, in real life it's not like that. Financially, emotionally, you know, family etc, it's just not as black and white as they, sort of, make out.[…] So I think you do need to be told. […] I think that needs to be, at least that needs to be accessible if you want it, if you want that." (John, 22, Administrator)

Quite few respondents highlighted the importance of receiving information regarding their legal rights. This information would allow them to make plans and take decision in regards to their return to work.

"Probably leaflet […] when it came to coming back to work about knowing your rights and knowing what your entitlement is. […] I think to be presented with the information so then you can make your own long term plans would be beneficial. you don't want to feel that information's being

withheld from you until the right moment. That's important for me to have all the information to hand." (Liam, 28, Electrician)

Respondents suggested other forms of communicating the aforementioned information than the traditional booklets and leaflets. They underlined the important of speaking in regards to these matters with professionals or with people who have been through similar experience or even the use of videos. They reported that this form of communication might be more beneficial.

"Think a booklet isn't, I don't think a booklet is the best thing. You'd just read through it and, sort of, put it to the back of your mind and think that's not you. I think you need to physically speak to people whether that be a nurse or cancer nurse or actually someone that's had cancer. You need to physically speak to someone. […]You need to find some common ground. Information could be in written form but you need to actually speak to someone." (Liam, 28, Electrician)

Furthermore, a respondent pointed out that information given to patients should be case specific and individualized rather than general. This would be more helpful to them and would match their needs at the time.

"I think that you have to be very careful with things like that and you can't make it general, and it has to be specific because I, you know, tried to seek advice and, you know, I still can't really find what I'm looking for because, you know, what I have is quite rare, […] so I've found it very difficult to seek the sort of advice that I need. […] I felt, you know, I just had to sort of deal with it. But I would say there's not enough honesty about what really can happen". (John, 22, Administrator)

However, a smaller percentage of the respondents felt that there was no need for any improvements in regards to their care and process of return to work. This was due to the necessary support they received at the time both from the hospital as well as from work.

> *"No I'm quite happy with everything - the way the treatment went, the way the work … people at work said, "Take whatever time off don't worry about it." So no I wouldn't change anything at all." (Nick, 56, Civil servant)*

One respondent stressed the importance of having time off after treatment and a phase return back to work as important elements on the recovery process.

> *"No, not at all [any changes necessary]. I had the op. I was off for eight weeks, went back part-time for eight weeks, had a week's holiday and then I went back full-time so, no, I wouldn't have done anything differently." (Helen, 46, Mortgage advisor)*

Some respondents reported that there was no need for them to receive any further information as they knew where to go if they needed to find out more about a topic.

> *"I must say, because I was at Charing Cross there was a little office-y thing there, you could go in and ask, so I was led to believe, all manner of questions if you wanted and that was open most days […] if you were worried about this or wanted advice or but I just thought I'll see how I go first and then it was there if I needed, you know, which is good." (Tim, 55, Carpenter)*

Another respondent said that there was not necessary to receive information

in regards to benefits as everything took place very fast and no such need emerged. The respondent acknowledged however, that this could be due to the fact that his condition was not as critical as others.

> *"I didn't [look into benefits to apply] because, as I say, I've been very lucky […] has been a lot quicker than I expected. [Money was] not an issue because I know they do a brilliant job […] I fell through the net and, luckily, it wasn't critical anyway." (Scott, 52, Delivery driver)*

4.1.5. Advice to other HNC survivors

Respondents supplied different advice for people with head and neck cancer who had concluded their cancer treatment.

One respondent pointed out the importance of information around cancer and encouraged other survivors to find out as much as possible about their condition in order to demystify issues around it and have a clearer idea about their situation. This could have a positive impact on their perception and find the benefits (i.e. positive changes) that may occur as a result of cancer.

> *"I think a lot of people see cancer as a huge dark cloud and it's the end. I've had it and it's not like that, not at all. […] get wise about whatever condition you've got. Check on the internet, go to the library or whatever, find out exactly what your situation is. Because that could be a positive thing it's not necessarily going to make you depressed." (Michael, 56, Technician)*

Some respondents focused on the importance of staying positive, finding an inner strength and not giving in to their condition.

"I think you just have to stay positive. I think a lot of it is mind over matter. Don't give into anything." (Helen, 46, Mortgage advisor)

"Yeah, the positive stuff comes from inside yourself you know. You can harden yourself up and you can toughen yourself up and you can work on yourself and that's fine." (Sonia, 34, Assistant manager)

Other respondents highlighted the important of people listening to their own body and not pushing themselves too much.

"You should learn to listen to your body, especially when you've been ill and I think many people that are ill still don't listen to their body even though their body is telling them, you know, you can't physically do something they just ignore it." (John, 22, Administrator)

"Well I would say if you can look forward, to not rush, you know erm to just maybe (laugh) take it easy. […] you know if you can look forward to take a lot of time out to relax before getting back to do it yeah. Yeah cos as well when you commit to something it might be difficult to you know to (11:18)….from that commitment. And then you find yourself stuck somewhere and you know feeling a big struggle to continue so." (Luke, 32, Musician)

Few respondents advised on "fighting" cancer and getting back on track with one's life following treatment. The respondents normalized the experience and urged people to seek for the help they need at any given time in order to keep carrying on and not let the illness take over their life.

"So my advice would be just to go and get on with it, get it done and get it behind you and get on with it afterwards because you don't … apart from a

few small issues you don't notice … you're not a different person you just get back on with your life." (Ben, 59, Foreman for scaffolding)

"Advise them is to not look back, carry on, fight like a soldier, you've only got one life, look after it.[…] No one's hard and that when things like that happen even the hardest of people can fall like a bag of shit. So you just got to get on with it, just fight it […] don't let it beat you, don't let grind you down […] Don't let cancer change your life.[…] just sort of like thinking, I've had cancer, I'm going to beat it and get on with life." (Erika, 47, Sales operator)

Many respondents urged others HNC survivors to return to work following their treatment. They acknowledged that requirements differ from job to job and that cancer affects people in different ways but they emphasized the importance of at least trying to get back to work as they found the process valuable and helpful. However, they also discourage people go back to work if they are not sufficient fit and ready for it.

"So my advice to people is just is go, just go for it, just don't sit back and feel sorry for yourself. It's not worth it. You've got to beat it. And going back to work is the best remedy and the best treatment you can have, once you get better and once you're on your feet." (Erika, 47, Sales operator)

"Don't come back [to work] before you're ready." (Anna, 46, nurse)

CHAPTER 5

RESULTS: T1-T2

5.1 VIEWS ON CANCER

This chapter presents respondents' views of the effect of cancer on their life as they expressed them both at baseline (T1) and follow up (T2) interviews. This theme emerged across themes and not pairwise.

5.1.1. The effect of cancer on HNC survivor's attitude and perception of life

Both at baseline interview as well as at follow-up respondents expressed their view of cancer and how it affected their life. They outlined the changes in their mentality and perception of life as well as changes in their everyday behaviour and lifestyle.

This theme incorporates data from both interviews in order to present attitude and perception as dynamic, changing responses to cancer. For many illnesses, adjustment and recovery are marked by important changes in attitude towards the illness – for example, with psychosis, many people progress from initial shock, through struggle and a search for meaning, towards acceptance (Romme & Escher, 1993). Beyond attitude towards the illness, onset and subsequent recovery from cancer are associated with change in wider perception of life (Petrie et al, 1999; Kucukkaya, 2010), an understandable psychological consequence of periods of considerable emotional turmoil (Eagly and Chaiken, 1995). It is worth noting that this theme was more often reported by respondents in T2.

Few respondents reported that the experience of cancer made them realize their vulnerability and human mortality and that both concepts had not occupied them in the past. They also mentioned a shift in taking pleasure in the simpler things that life offers.

"I would say that I feel a little bit more vulnerable now you know than before I felt pretty immune that you know cancer is not going to happen to me you know and then it did happened and I thought about and I should have really think about things but I haven't bothered to really think about things. But um I suppose that having cancer has made me feel a little bit vulnerable you know you've got to sort of look at things differently." (Michael, 56, Technician)

Some respondents said that their attitude changed in that they do not get upset about everyday things anymore.

"I think oh well there's no point in getting uptight about that, it's not the end of the world - I've just taken a different approach really." (Susan, 47, HR manager)

"After you've been through this thing you don't get nervous about anything." (Paul, 40, Brooker)

Many respondents discussed how cancer has helped them reflect in their life and changed their perception drastically in that they came to realize what is really important and made necessary lifestyle changes. They felt that cancer has been of benefit as it helped them reassess and improve the quality of their life.

"So the cancer itself it's not even a triggering factor. It's simply something that stopped me in my tracks, and made me reflect what the hell I'm doing with my life." (Blake, 61, Teacher secondary)

However, few respondents reported that cancer did not affect them in any way in that they continue value life as much as they did before or it did not made them worry everyday things less.

> *"Now I have asked myself, seriously, am I valuing every minute of every day, and no, frankly. I don't feel any different. […] I mean I don't I can't honestly put my hand on my heart and say, I now value life as I thing, more than I did before. I mean I value the same things that I valued before, and a lot of those were very life enhancing […] I value those just as much as I did before, but certainly no more. I couldn't value them any more; I mean they are just as essential as they were." (Terry, 46, Police advisor)*

> *"Well you think you're going to, but you're still subject to the same sort of pressures and influences that you normally get. So it's difficult you think initially that you're going to be different and you're going to treat life differently, and perhaps there is a small element of that, but largely I'm just the same as I ever was I think. […] was conscious of the fact that there's more things in life to worry about than the little things you used to worry about. But I find I'm still worrying about the little things now." (Ben, 59, Foreman for scaffolding)*

CHAPTER 6

DISCUSSION

The present study aimed to explore the experience of HNC survivors upon return to work over a 1-year period post-treatment. A qualitative approach was employed and semi-structured interviews were conducted which allowed investigation of a number of psychosocial themes across two different timelines; four weeks after treatment and twelve months onwards. The outcomes of this study inform on the key issues that emerge when HNC survivors return to employment and discusses potential applications in the context of facilitating return to work. Possible limitations of this project along with suggestions for future research are also presented.

6.1 SUMMARY OF THE EMERGED THEMES AND LINKS TO LITERATURE

The main themes from this study were grouped into six categories: 1) Reorientation and financial issues as the main reasons for returning to work, 2) Difficulties in readjusting to working conditions, 3) Stigma around cancer and an example of its manifestation, 4) Proposed improvements for the care of HNC survivors to facilitate return to work, 5) The effect of cancer on attitude, perception of life and work, and 6) Advice to other HNC survivors. They are summarized below and presented along with interpretations of their meaning and links to literature that show how they contribute and expand our current knowledge.

6.1.1. Reorientation and financial issues as the main reasons for returning to work

At the first interview, most respondents who were due to return to work following treatment indicated that their main reason was to avoid feeling bored at home. They wanted to go back into their working regime and normal routine. However, some of them were concerned whether they would manage to return successfully given their physical difficulties at the

time. For others it was because of financial pressures. They were feeling obliged not to fail meeting their commitments such as their children's needs.

Respondents who had already returned to work or kept working during treatment did so because they had no significant symptoms or side effects and felt capable to maintain the working position. Others felt that they did not want to stay at home idle-handed. They preferred to be in a working environment and be productive. Some respondents were forced to keep working during treatment because they were not receiving any sick pay and had financial concerns.

These findings indicate that patients with history of HNC were able to return to work or keep working during treatment either for personal benefit or financial pressures. A study by Amir, Neary and Luker (2008) has also found that the principal reasons for cancer survivors to return to employment were a quest for normality and financial pressures. Their motivation in returning to work is a milestone as it can be seen as an important part for those who wish to transit from a patient to a survivor status. Grunfeld and Cooper (2010) have also shown that work symbolizes normality for patients who reported that work allow them to regain their previous lives. Furthermore, motivation has been shown to be a prerequisite for a successful vocational rehabilitation (Berglind and Gerner, 2002; Isaksson Mettävainio and Ahlgren, 2004). The reassertion of their identity as a worker rather than as a patient is important to those who wanted to return to employment for personal gains although some were feeling apprehensive about their fitness to work. Respondents' perceptions of the role of work in their life circumstances and their perceptions of self-efficacy may provide further insight into the differences in return to work behaviours among HNC survivors. The experience of those respondents, who felt obliged to return to work for financial reasons, indicates the relatively modest levels of

financial protection available to workers with medical problems. This finding reflects the current social welfare context in the UK and may sensitize changes in policy.

For many people of working age returning to paid work after cancer treatment is an important milestone in the transition from patient to survivor and an attempt to regain normality and financial security (e.g. Peteet 2000; Amir et al, 2008; Grunfeld and Cooper 2010; Steiner et al, 2004; Ferrell and Dow, 1997). This is ever more important given the increasing incidence of cancer diagnoses, higher survival rates, and extension of working life in industrialized societies, all serving to establish an increased number of employees with cancer history (Bradley and Bednarek, 2002; Kennedy et al, 2007). Findings from the present study suggest that HNC survivors follow a common path with other cancer survivors back to work and normality.

Furthermore, the present study supported the wider literature in showing how people's decisions about paid work reflect a complex context of individual, household circumstances and the collective social welfare provision of the country regarding access to health care services and cash benefits. This is consistent with research showing that the employment status of individuals following cancer treatment may vary from one country to another depending on the financial support that a state offers for people with a chronic illness (Taskila and Lindbohm (2007), or the social provision (Spelten and colleagues, 2003) play an important role to individuals who decide to return back to employment. Again, in the USA cancer survivors are more motivated or compelled to remain at work to maintain their health insurance coverage (Bradley and Bednarek, 2002) and that returning to work after a disabling illness is related less to the actual illness than to having

alternative resources for financial support (Chirikos, Russell-Jacobs, Cantor, 2002).

6.1.2. Difficulties in readjusting to working conditions

At the baseline interview, although some respondents who were due to return to work in due course felt that they would not face any difficulties in the process and they would be able to carry out all tasks, most of them anticipated that they may encounter difficulties. These were in relation to the nature and demands of their work and their lack of confidence after being off work for some time. They also predicted physical difficulties emphasising communication problems and fatigue, cognitive challenges involving information processing speed, memory and concentration, and emotional problems such as feeling depressed. Finally, they also reported potential difficulties in their interaction with work colleagues following disclosure of their condition. Most of them however, had informed their employers about their condition and were reassured for a phased return (i.e. gradual) to ease them back to work. This involved flexibility from the employers' perspective in regards to return to work date and working hours while keeping them in full salary.

A similar pattern was found among respondents who either continued working during treatment or had already returned to work. Many of them found the process easy and were back to their normal working regime without specific difficulties. Some of them emphasized that the support of their colleagues was particularly useful in their process of resuming their work duties. Yet, some respondents encountered difficulties with regard to fatigue and other people's indiscreet reactions towards their condition upon disclosure. While some of them benefited from their employers' allowances in working fewer hours, others had not the same experience. They found their employers lacked understanding of the impact of cancer treatment and

its disabling and long-lasting side-effects which resulted in removing reasonable adjustments initially put in place to support them.

A year following the first interview, the baseline's findings had remained along the same lines. Few respondents did not report any difficulties upon return to work explaining that this was due to their lack of physical or psychological symptoms and stressed the important contribution of their colleagues' support, which eased them back to work. Yet, most respondents reported that they experienced mild or moderate difficulties. Although for some of them their difficulties resolved themselves with time, most of them found their physical difficulties in regards to movements, communication and fatigue and their cognitive problems with memory and concentration, challenging. Few respondents reiterated difficulties in their interactions with colleagues following disclosure of their condition. However, when possible, some attempted to work around their difficulties by making necessary adaptations or took advantage of their employer's allowances or working less hours while being on full salary and resume their duties at their own pace. Few respondents also reported that their employers lowered their expectations in regards to performance assisting them by that way to cope more effectively. Yet, other respondents' experience of their employers was different. The latter were inflexible and did not allow any accommodation for their employees' needs. Some respondents stressed that dealing with work issues while still feeling unfit may have hindered their recovery and because of financial pressures they could not postpone their return to work nor take any time off, as they would not be on payroll.

Not surprisingly, respondents either anticipated or experienced a range of difficulties due to residual symptoms upon return to work or while working, respectively. The impact on these symptoms could either delay return to work or render readjustment difficult. This is a well documented

finding given the nature of their condition and its treatment side-effects (e.g. Kennedy, Haslam, Munir, Pryce, 2007; Spelten et al, 2003; Grunfeld and Cooper, 2010; Abrahamsen, Loge, Hannisdal, Holte, Kvaløy, 1998). This was also true in cases were patients who reported returning to work sooner due to financial pressures. Studies have shown that these patients may experience fatigue, which can exacerbate their condition and delay their work adjustment (Pryce et al, 2007; Kennedy et al, 2007). Yet, although some respondents benefited from their employers' support, others were challenged further by their employers' inflexibility and lack of understanding of their condition. Other studies have found similar results (e.g. Kennedy et al, 2007). This is particularly important as it highlights the employers' responsibility and role in the vocational rehabilitation process of cancer patients upon return to work. Evidence from literature also suggests that employers' allowances are a pivotal factor not only in the successful return to work but also in the maintenance of employment (Booknight, Bradley, Luo, 2006; Baanders, Andries, Rijiken, Dekker, 2001). For example, the majority of companies have reported that they provide phased returns (i.e. allowances with regard to working hours and workload) to their employees in order to return gradually to work (Grunfeld, Rixon, Eaton, Cooper, 2008) and studies have shown that this approach can help boost well-being and confidence (Taskila and Lindbohm, 2007). However, a study by Larson and Gard (2003) found that although employers are aware that there is still space for improvement in the psychosocial environment that workplaces provide, they also stressed that at times organizational and financial issues may obstruct this process. Yet, the importance to increase awareness and understanding within an organization so that they can put more practical support into place, remains (Taskila and Lindbohm, 2007) and the fact that the latter have expressed interest in receiving information to identify and support their employees' needs, is encouraging (Grunfeld et al, 2008). Finally, some participants also stressed that their successful return

to work was also facilitated by their work colleagues. A previous study has also demonstrated that cancer survivors received most support from other coworkers and they were satisfied by this support (Taskila, Lindbohm, Martikainen, Lehto, Hakanen, Hietanen, 2006).

Unfortunately, respondents' concern for potential difficulties with work colleagues upon disclosure of their condition was proven valid in that their interactions and dynamic relationship with colleagues had changed. Respondents reported that the latter were neither always discreet nor supportive towards them. Another study by Staley, Kagle and Hatfield (1988) on patients' experience and interactions with co-workers upon disclosure had similar findings. They indicated that both patients who continued working during treatment and those who returned to work after their therapy were often apprehensive about their co-workers' response. They also found that some faced changed and difficult interactions with their work peers. This finding reflects preconceptions around cancer and its stigma both from the patients' as well as other peoples' perspective. Studies have found that co-workers often attribute their behaviour to concern about the cancer patient's health or work performance, yet this illustrates the stigma, fear and misinformation still associated with cancer (Sontag, 1977; Cantor, 1978; King, 1982). Previous research has also shown that the stigma experienced following a diagnosis of cancer is due, at least partly, to a "cultural fear" of cancer and its associated concepts of threat, suffering and death battle (Flannagan and Holmes, 2000). Thus, disclosure of cancer may trigger fear of stigmatization in patients (Knapp-Oliver and Moyer, 2009) and evoke negative feelings in others (Dakof and Taylor, 1990). However, the nature of the relationship with co-workers represents a significant social milieu and reference group for cancer patients and influences their feeling of job satisfaction. Given that this can potentially be influential in patients' decision to remain at work; it is an issue, which should be addressed. Yet,

because co-workers' behaviours and attitudes are not circumscribed by legislation or by fear of legal action, it could be more challenging to control. However, it is still possible for some actions to take place following organisations' initiative at a local level.

As already discussed, it is known in the literature that mixed type cancer patients face difficulties when return to work which are related to the nature of their job (e.g. Greenwald et al, 1989; Berry, 1993; Ganz et al, 1996; Satariano and De-Lorenze, 1996), their own physical symptoms (e.g. Verbeek et al, 2003; Maunsell et al, 1999) and relationships with colleagues (e.g. Staley et al, 1988). Few studies on HNC survivors in particular also showed that the demands of the job (Schraub et al, 1995) and their physical symptoms following specific HNC treatment render difficult their attempt to return to employment (Verdonck-de Leeuw et al, 2010). The present study provided further qualitative insights with regard to these difficulties for HNC survivors. As it is widely accepted, HNC is a disfiguring experience around the head and neck regions and this might cause functional loss, for example in voice and speech (e.g. Langius and Lind, 1995; Hoffman, Ehrenfeld, Hwang and Schwenzer, 1998; Lin, Chang and Lee, 2000; Epstein, Robertson, Emerton, Philips and Stevenson-Moore, 2001), which result in particular difficulties at the workplace that are specific to this type of cancer. This study showed that disclosure of HNC along with its visible disfigurement following treatment can elicit undesirable responses from other people and individuals' difficulties in communication impacted their interpersonal relationships. HNC survivors who returned to work faced challenging relationships with their colleagues, which is line with findings from studies with mixed type of cancer survivors (e.g. Staley et al, 1988). These individuals often experience distress caused by their facial disfigurement and its consequences, which is linked to the importance of the facial region to a person's identify, self-image and successful interactions

with others (List, Siston, Haraf, Schumm, Kies, Stenson and Vokes, 1999; Lockhart, 2000). This experience is again more related to HNC and enriches our understanding of the issues relevant to individuals with this type of cancer history who return to employment. These findings can advise current vocational rehabilitation practices, which can support HNC survivors to better manage their physical symptoms and psychological services to target co-workers by providing specific information about HNC in order to facilitate good working relationships.

6.1.3. Stigma around cancer and an example of its manifestation

Although most HNC survivors disclosed their condition to their employers, there were a few who refrained from doing so. Their reasoning was to avoid preconceptions about cancer and their potential unwanted consequences such as questioning their ability to perform the work tasks.

Other studies have also shown that cancer patients refrain from disclosing their condition to their employers (Pryce et al, 2007). Unfortunately, there is evidence that employers do have negative perceptions related to people with disability, which can potential impact on the employment and retention of these individuals (Amir, Strauser and Chan, 2009).

This finding illustrates that stigmatization around cancer is still prevalent both from the patients' as well as the employers' perspective. Stigmatization regards attitudes and beliefs about patients' health and ability to continue their jobs and the latter may be shunned or treated coolly at the workplace (King, 1982). Given that cancer is usually associated with death (Flannagan and Holmes, 200) it is understandable why preconceptions about cancer trigger such responses. Yet, the number of survivors who return to work has increased due to improvements in treatment survival rates and they have shown to have a successful and productive return to their workplace

(Bradley and Bednarek, 2002; Kennedy et al, 2007). Thus, it is concerning that these beliefs still prevail despite encouraging and positive evidence. This is particularly important in the context that disclosure is a pre-requirement for HNC survivors to receive adequate support from their employers upon return to work such as allowing them time off to attend hospital appointment or making suitable adjustments to the workplace to meet their needs.

This study also revealed differences in the employers' response when they were informed about their employees' condition. Whilst some employers responded positively by keeping in contact with their employees during treatment or putting them in contact with the relevant welfare departments, others' response was not helpful. Patients revealed that the latter either ceased or had limited contact with them during treatment and found difficult to access them in order to receive important information, for example with regards to sick pay. This discrepancy between the employers may be interpreted as a manifestation of how stigma can affect employers' decisions and shape their responses as Amir et al, (2009) indicated in their study.

Literature has shown that cancer patients avoid disclosing their condition to their employers out of fears of stigmatization (Pryce et al, 2007). This study showed that this is also true for some HNC survivors who return to work. Yet, as it is known, HNC treatment's side effects may lead to disfigurement and functional loss such as speech and voice difficulties, which can impact individuals' ability to perform their duties at work (e.g. communicating with colleagues or clients). This might result in disadvantages in labour market for HNC survivors, who might be perceived as less employable or might face demotion and lower wages. Thus, the finding that HNC survivors, who return to work might avoid disclosing their condition can be related to the

negative work consequences they might confront due to the side effects of their cancer treatment. However, as it was reported, employees are more likely to disclose their condition at work if they perceived receiving support from their line managers in relation to their chronic illness as important (Munir et al, 2004, 2006). This can lead to a constructive dialogue between the two parties with regards to reasonable work adjustments in order facilitate work retention. But, at the same time, as Amir et al, (2009) pointed out, employers need to be provided with training, support and resources to help them facilitate employment and job retention of employees with cancer history. As the present study showed, some employers were not adequately equipped to provide this support to their employees with cancer history and this led the latter to experience negative consequences upon return to employment. Thus, it can be concluded that this findings have significant implications for the nature of work that a clinical psychologist could undertake in order to bridge the communication between employers and employees who return to work following HNC cancer treatment. The latter can focus on the dysfunctional and negative beliefs of the HNC cancer survivors with regards to disclosing their condition at work and enrich the knowledge and skills of employers to manage employees with this type of cancer history.

6.1.4. Proposed improvements for the care of HNC survivors to facilitate return to work

Respondents drew information from their own experience and suggested further improvements within the current system, which could improve the care of other HNC survivors and facilitate their return or stay at work.

Many respondents stressed the importance of more information and support on different issues around their circumstances. They indicated the need to know more about possible up and coming consequences with regards to their physical and emotional health, potential financial implications and

information about return to work and their legal rights. Some respondents also mentioned that they would prefer to receive an objective debrief rather than an overly optimistic one which would allow them to plan accordingly. In addition, respondents suggested that the information given would be more helpful and meaningful to them if it was case specific and individualized given that different cancer types trigger different symptoms and needs. They also proposed alternative forms of communicating this information rather than the traditional booklets and leaflets. They suggested that being able to talk with someone or seeing videos would make it easier for them to have access to this information but more importantly to comprehend them.

Respondents reported that the NHS system needs to be more flexible with regards to appointments. They explained that they were often being offered many appointments at different dates, which rendered it difficult for them to keep up with their work and other commitments such as their children's needs. Respondents felt that this was an inconsistent message from health care professionals who whilst they were advising them to keep a work/life balance at the same time were hindering the patients' attempt themselves by being inflexible with hospital appointments. This led them to question the "holistic approach" of the system, which appeared to fall short in the coordination of their care. They also added that this practice has an extra financial cost to them for having to travel often to the hospital and although they could claim this money back, they pointed out that this is a governmental expense, which could be avoided. Thus, they suggested the appointment of a care coordinator to assist in the liaison and communication between professionals and orchestrate their care.

Some respondents pointed out that being able to have time off work to attend hospital appointments is very important as it allows them to balance

work and cancer treatment. However, some employers forced them to use annual or unpaid leave, which had a financial or personal cost to them and added an extra stressor into their life.

Respondents suggested that there is need for further support on an emotional level to be put in place, especially following an operation. They indicated that the psychological scars after such a procedure leaves them vulnerable and weak which renders the process in looking for counseling themselves even more daunting.

Other respondents discussed how having to take time off work and try to keep up with their other responsibilities such as family needs can be financially perilous. This experience can add further turmoil and worry into their situation at the time and worsen their condition. They explained that being physically unfit makes it very hard for them to find out information and complete applications to receive benefits. Thus, they suggested the need of having some help into place so that someone could assist them with the application process.

Finally, some respondents suggested the need for HR to commit further to its role. They explained that HR could improve its services and become more competent by increasing its awareness and understanding of cancer and the impact of treatment. As a consequence, HR can have a key role in assisting HNC survivors return to employment by providing them the necessary support such as information about insurance policy and having realistic expectations of them, for example when to return to work.

Yet, fewer respondents reported that there was no need for any improvement with regard to the current care system and the process of returning to employment. They explained that this was due to receiving the

necessary support both from the hospital as well as from their employers. Respondents pointed out the importance of knowing where to refer to should they needed any further information with regard to their condition, benefits and return to work advice. The also emphasized the advantages of being allowed having time off after treatment and have a phase return back to work as key elements of their recovery process. However, they reflected that their experience could be due to their cancer type and less severe symptomatology in comparison to other patients and the fact that they went very fast through the treatment process.

The above findings draw attention to a number of points.

Firstly, although Back and Bail's work (2003) has already indicated that cancer survivors are willing to discuss with their healthcare professionals the impact of their cancer on other aspects of their lives apart from the medical side; this does not appear to be the case in current clinical practices. In this study, respondents reiterated their need to receive more information. This is a replicated finding from previous studies which have shown that there is lack of information and advice from health professionals about work issues and individual's capacity to perform work tasks (Maunsell, Brisson, Dubois, Lauzier, Fraser, 1999; Main, Nowels, Cavender, Etschmaier, Steiner, 2005; Amir et al, 2008). In addition, although respondents requested information to be case specific, it is known that it is difficult for health professionals to give accurate individual advice due to the diverse nature of reactions to the treatments (Mock, 1998). Furthermore, respondents suggested that having someone to discuss or having access to videos to receive this information would be more advantageous than traditional booklets and leaflets. Indeed, Clark (2004) has argued that since healthcare staff is usually the first and most influential source of information for cancer survivors, they can support them on this. In addition, it is known that

people process information through two basic channels, verbal and visual (Mayer 2001, 2003). Thus multimedia features can be more helpful to them than booklets.

The finding in regards to the inflexibility of the NHS with hospital appointments which clashes with patients' work/life responsibilities reflects the challenges that current clinical practices face to get a balance between providing optimal care and governmental budget and personnel cuts. NHS's challenges to meet cancer patients' needs have also been indicated in other studies (e.g. Willard and Luker, 2005). As a consequence, patients shoulder this burden while at the same time trying to poise health needs, family, work and other responsibilities.

Respondents revealed how different responses from their employers were either helpful or no while the former try to balance work commitments and their health care needs by attending hospital appointments. This finding reflects that there is wide diversity among organizations in their capacity to offer flexible arrangements. Yet, it also points out the important role that employers play in assisting patients to remain at work while receiving treatment. This emphasizes the need for flexibility from the employers' perspective, which has been shown in several studies (Booknight, Bradley, Luo, 2006; Baanders, Andries, Rijiken, Dekker, 2001). In addition, it may concur with the suggestion that some employers' fail to make adequate provisions due to a culture of ignorance within organizations about the needs of employees with cancer and their unawareness of the services and support that they could provide (Morell and Pryce, 2005).

The need for counseling following operation to address their emotional needs is an unsurprising finding. Yet, despite the wide availability of psychological health services aiming to help patients cope with distressing

physical symptoms and improve their quality of life (Fielding and Latchford, 1999 for a review) it appears that their access is not readily available to patients following surgery. Pryce, Munir and Haslam (2007) found that only few employees are offered counseling in regards to emotional issues relating to residual concerns following cancer which in not unlikely to affect return to work rates.

Respondents pointed out that having support in identifying and completing application to receive benefits would be useful to them. This is particularly important in the context of their poor physical health at the time. Thus, this finding reflects the lack or inadequacy of such services within the care system. Another study has also shown that patients welcome advice and help in regards to medical benefits application process (Frazier, Miller, Miller, Horbelt, Delmore, Ahlers-Schimdit, 2009).

The indication that HR services could improve their offering is a concerning finding. Existing literature has also highlighted the challenges HR faces when dealing with cancer survivors returning to employment (Pynes, 2004). This reflects current inadequacy to address needs of employees with history of cancer which may potentially impact in the latter's recovery process as well as have a role in the reduced number of patients who return to employment. In fact, organizations have already indicated that there are several services, which they could improve, in order to be more supportive towards cancer survivors who return to work (Grunfeld et al, 2008), which is promising given that they are aiming to be more supportive.

Therefore, existing literature has already indicated that current information and advice from health professionals about work need to be enriched (e.g Maunsell et al, 1999), the struggles NHS faces to meet patients' needs (e.g. Willard and Luker, 2005), the importance of employers to be flexible (e.g.

Booknight et al, 2006), the not readily available counselling services for emotional issues after surgery (e.g. Pryce et al, 2007), the need of support for medical benefit application processes from the care system (e.g. Frazier et al, 2009) and finally, the importance of HR to improve their services to employees (e.g. Pynes, 2004). Current findings, contribute to existing literature by providing an in-depth explorative approach and a more targeted focus for an intervention to take place by giving indications as to where efforts can be directed. Findings consisted of qualitative and practical information from HNC survivors on how to improve current practices to facilitate return to work for individuals with HNC history who attempt to return to work. Although overall these suggestions are in line with current thinking of how current practices can improve in order to support return to employment for cancer patients in general, some are more related to the nature of HNC cancer and thus enrich existing knowledge on this topic. For example, the request to receive more information with regards to physical and emotional health and return to work specific to their type of cancer is particularly important as it would allow them to make informed decisions with regards to their work and life. Also, their suggestion to receive emotional support after surgery is directly linked with the visibility of the disease, which also leaves psychological scars following treatment. This can shape the nature of the emotional support to be provided, in that it could target feelings of loss (e.g. physical appearance, identity, self-image, social life) due to disfigurement and its psychological consequences such as distress. Finally, their indication that HR services could improve their offerings and adjust expectations at the workplace was again specific to the nature of HNC cancer and its particular side effects following treatment. Overall, it can be concluded that existing services can be updated and additional ones can be developed in order to better reflect the specific needs of HNC cancer survivors. Section 6.2 below provides some suggestions with regards to these services.

6.1.5. The effect of cancer on attitude, perception of life and work

This study extracted information from patients' narratives both from the first as well as at the follow-up interview and found how patients' mentality, perception of life and behaviour had changed following the experience of cancer. They revealed that it made them realize their vulnerability and human mortality for the first time and how this shifted their attention into taking pleasure in the simpler things that life offers. They also reported becoming more patient with everyday's challenges, which in the past used to upset them. On the whole, respondents discussed how cancer helped them reflect on in their life and make necessary lifestyle changes, which improved the quality of their life. Only few respondents however, reported that the cancer experience did not affect them in any way as they were equally valuing life or worrying about everyday things as much as they did in the past.

The role of work in their life was a topic that the cancer experience had an impact on their perception. Many respondents viewed work positively before diagnosis and this view remained so after treatment. They valued the opportunity working in a nice environment, the nature of the work, which gave them a sense of achievement and satisfaction, the financial gains and the social relationships with their colleagues. Yet, some of them began to value work even more after cancer and appreciated further the fact that they are still able to perform in the workplace. Many respondents reported that they still had work-related goals which they wished to achieve. For example, some wanted to develop further their skills and their competence within their workplace; other wanted to be promoted; one to expand his private business; and some others to make a career change. Yet, many of them reported that they wished to achieve a better balance in their life and work and pursue more actively their hobbies and dreams. On the other hand, for some respondents the experience of cancer had a different effect on their

perception of work. They reported that whilst in the past work had a predominant role in their life, this has changed and were less concerned and preoccupied with work after cancer. They had no aspirations or further goals with regard to work and they reported being content with their current status. Some mentioned that this was due to their age or due to the consequences of having had cancer as they were not prepared to take on any further physical or psychological challenges, which may worsen their condition. For many of them, their priorities had shifted and were keener now to focus on their family and improve their lifestyle.

Although few respondents reported that cancer did not alter them in any way, most admitted that the experience of cancer altered their perception of life and affected their attitude and behaviour. They explained that they improved their lifestyle to achieve a better quality of life and began taking pleasure in what life had to offer. This finding replicates previous studies which have shown that positive changes can occur following cancer such as adapting a healthier lifestyle (Petrie, Buick, Weinman, Booth, 1999) or feeling a greater appreciation of life Kucukkaya, 2010). Respondents also mentioned that their attitude and goals towards work changed after cancer. For few, work became even more important following cancer and they were still aspired to pursue work-related goals but keeping them in balance with life goals. However, others reported that they had no motivation to pursue any further work goals and that their priorities have shifted and wished to focus more on their family and acquire a better lifestyle. This is in line with previous findings, which showed that patients' value of work changes following cancer (Grunfeld and Cooper, 2010) and that they question the relevance of work and re-evaluate their priorities (Kennedy et al, 2007; Parsons, Eakin, Bell, France, Davis, 2008). Such findings can be related to the theory of cognitive adaptation, which suggests that after threatening events people attempt to cope with and find meaning (Taylor, 1983). The theory

suggests that people use this strategy as a defense mechanism and try to see the good in the negative event in order to learn from it. By attempting to regain mastery to structure their life again, individuals re-build their self-esteem and a positive self-image following a traumatic event.

Previous studies with other types of cancer survivors showed that the experience of cancer leads to changes in perception of life (Petrie et al, 1999; Kucukkaya, 2010) and work (Grunfeld and Cooper, 2010; Kennedy et al, 2007; Parsons et al, 2008). The present study indicated that these changes occur also in HNC survivors and are in line with findings from other studies with mixed cancer types individuals such as patients with history of breast, urological and gynaecological cancer. As it is widely accepted having cancer around the head and neck regions is a disfiguring and highly distressing experience due to its visibility, disfigurement and communication difficulties, which affect everyday functioning in social situations, and can have a more direct effect on the individual's identity and interactions/relationships with others (e.g. List et al, 1999; Lockhart, 2000) both at workplace and personal life. This might contribute to the individuals' changes in attitude and perception and it could affect the process of returning and remaining at work, both for the individual as well as the employer and thus needs to be taken into consideration. These changes in perception of life and work are related to the specific nature of HNC experience with reference both to the physical and emotional consequences of the disease.

6.1.6. Advice to other HNC survivors

Respondents drew from their own experience and provided advice for other people with head and neck cancer. They encouraged other survivors to seek as much information as possible about their condition in order to have a clearer view of their situation, which would also help them realize the

positive effects that their illness can have on them. Others insisted on the importance of listening to one's own body, seeking for help when needed and staying positive in order to find an inner strength to "fight" cancer. They invited them to actively attempt getting back on track with their life and suggested that returning to employment can be part of this. However, even if getting back to work is rewarding, they discourage them doing so if they do not feel sufficiently fit.

The advice to find out information about cancer and on related issues as well as to seek help when needed, it is particularly important as it can assist HNC survivors to understand their body better but also to know how to act and make plans. This can be linked to action space in the theory of actions which suggests that people in order to know how to act must be aware of their action space (as cited in Jansson and Björklund, 2007, p130). Furthermore, a study has shown that the extent of available information about disease severity and prognosis had a greater influence on adjustment than did the severity of the disease (Kreitier, Chaitchic, Rapoport, Algor, 1995). Respondents' encouragement to look for the positive impact of cancer echoes what is known in psychology as "benefit finding". Benefit finding refers to an active search for meaning and cognitive adaptation as a result of challenging life events such as cancer which leads to personal growth (e,g, Antoni, Lehman, Kilbourn, Boyers, Culver, Alferi, Yount, McGregor, Arena, Harris, Price, Carver, 2001; Andrykowski, Brady, Hunt, 1993). For example, some individuals report that they appreciate more their own strength and resilience, feel emotionally closer to others, become more altruistic and their life philosophy changes in that they cite an enhanced appreciation of what life offers and redirect their priorities. Patients' perceptions after having cancer which triggers positive life changes in spite of its distressing effects has been the focus of many studies (e.g. Lechner, Zakowski, Antoni, Greenhawt, Block, Block, 2003). The ability to find benefits after threatening

situations has particular relevance for people dealing with life-threatening diseases such as cancer (Carver, 1998) as it may assist them to adjust better. For example, studies have observed relationships between benefit finding and higher levels of well-being (Coward, 1991) lower levels of distress (Fife, 1995), higher self-esteem and less anxiety (Lewis, 1989). Respondents also advised other survivors to return to work as they found it a valuable experience themselves but not unless they are fit enough. A previous study has shown how important it is for patients to return to work as they gain a perceived sense of control in their lives (Peteet, 2000). Yet, it is crucial that the time to return to work is right because if patients go back to employment too soon they may experience greater fatigue (Pryce et al, 2007; Amir et al, 2008).

This finding expands current literature by providing insightful advice from HNC survivors around the experience of cancer to individuals who recently received a similar diagnosis. The suggestions with regards to seek for in-depth advice regarding HNC and ask for help when needed were linked with the action space in the theory of actions in that people need to be aware of what options are available to them (action space) in order to know how to act. The suggestions about keeping a fighting spirit and stay positive throughout the cancer experience were associated with the concept of benefit finding in challenging situations. These links enrich current knowledge and thinking of the HNC experience as they both show how important it is for HNC survivors to understand and accept the disease and its consequences, which in return can empower them to feel more in control and adjust accordingly their lifestyle. Finally, the encouragement to resume their life as well as to return back to employment was unexpected in that HNC survivors report more problems when return to work than individuals with other type of cancers (e.g. Wooden et al, 1992) and have the highest adjusted risk of disability (Spelten et al, 2002; Short et al, 2005). Therefore,

this is encouraging and coordinated efforts to assist HNC survivors to better manage their cancer-related symptoms are imperative, in order to facilitate their return to employment.

6.2 POTENTIAL APPLICATIONS OF FINDINGS

Outcomes of this study indicate that HNC survivors are challenged with multiphase difficulties and barriers in their attempt to return back to working life. This renders the "returning to work" phenomenon not simply an individual problem but an interactive one between patients and other structural environmental aspects such at the NHS and their workplace. The following suggestions aim to capture this dynamic and provide applications to address all the relevant parties.

Overall, the findings of this study indicated that patients have a clear need for further support in order to make progress in their vocational rehabilitation. Previous research has also reach to similar conclusions (e.g. (Holmgren and Ivanoff, 2004; Isaksson, Mettävainio and Ahlgren, 2005). In order to address this need, four different areas of potential interventions have been identified which may contribute in the successful journey back to employment for HNC survivors.

6.2.1. Additions in the healthcare professionals' duties

Although, healthcare professionals' primary responsibility is to provide quality cancer care, they could also be the first reference point for patients to extract information in regards to employment, insurance consequences of cancer and offer guidance to further resources for information and assistance. This information along with a realistic account of the persons' health condition would assist informed decisions in regards to work timing and the capacity of patients to perform work tasks. Kennedy and colleagues (2007) has also indicated that there is space for further improvement related

to advice in regards to work and information given to patients by health professionals. It was suggested that such advice and information from cancer specialists can increase return to work rates (Amir et al, 2008). Yet, it is crucial that this information is communicated as competent as possible in order to improve readiness to return to work rates and work issues such as side-effect management. Understandably, this may be considered as an additional pressure for healthcare stuff, yet it is crucial that time is found and systems develop so that more cancer survivors succeed to return to employment. A preferably complimentary, rather than alternative suggestion would be the production of a DVD with relevant information in an audit-visual format to be given to HNC survivors as a further source of such information along with the provision of related booklets and leaflets. Furthermore, Guy's and St Thomas' hospital offered recently a telephone based service run by cancer nurses in order to enhance the quality of life of breast and prostate cancer survivors. Expanding this service to other types of cancer as well might be an alternative additional offering.

6.2.2. Psychological input

Specialized psychological services may put into place to address the physical, cognitive and emotional symptoms of HNC survivors following treatment. Symptoms such as fatigue, memory difficulties and depression may lead to reduced work hours and occupational role changes. Thus, psychological interventions aiming to provide specific techniques such as pacing, mnemonics and relaxation techniques to address these symptoms can assist patient to manage their condition more effectively and improve their work capacity. Other studies have also pointed out that by addressing these symptoms barriers to work may reduce (e.g. Steiner, Cavender, Nowels, Beaty, Bradley and Fairclough, 2008; Spelten et al, 2003; Grunfeld and Cooper, 2010; de Boer et al, 2008; Jansson and Björklund, 2007). In addition, healthcare professionals could inquire in details about the impact

of symptoms on work in order to identify patients who could benefit from such interventions and refer them to the relevant services.

Furthermore, cancer patients' beliefs and expectations about their work abilities are an important factor in the return to work process (de Boer et al, 2008) and may shed light into why other adequately fit survivors may not return to work following treatment. Our study showed that patients with HNC history are concerned whether they would be physical able to cope with the return to employment process. Thus, reorientation in one's life situation where understanding for this transition process along with a feasible rehabilitation plan and encouragement can be provided in the form of group activities or individual sessions may potentially be very useful. The need for psychological interventions aiming to address the beliefs cancer patients form about their condition and ability to work has also been indicated by other experts in the field (e.g. Grunfeld and Cooper, 2010; Grunfeld et al, 2010). There is already evidence which indicates that rehabilitation programmes for patients on long-term sick leave can improve perceived work ability (Braathen, Veiersted and Heggenes, 2007). Also, interventions aiming specifically to reframe illness representations have shown to be effective, even if they are brief (Petrie, Cameron, Ellis, Buick, Weinman, 2002). As a consequence of such interventions, the number of HNC survivors who return to work may increase.

The key role of employers to identify employees who struggle following return to work has been demonstrated in previous research (Grunfeld et al, 2008; Holmgren and Ivanoff, 2007). Employers can subsequently evaluate fairly their employees' performance and make informed decisions regarding reasonable adjustments to the workplace so that needs are met. Yet, this study indicated that some HNC survivors did not disclose their condition to their employers due to preconceptions about cancer, which echo feelings of

stigmatization. Another study has also found that less than two-thirds of cancer survivors disclosed their cancer to line managers upon return to work (Pryce et al, 2007). Furthermore, a survey of patients with other chronic illnesses such as arthritis, musculoskeletal pain, diabetes, asthma, migraine, heart disease, irritable bowel syndrome and depression showed that only half of respondents disclosed their chronic illness to their line manager (Munir, Leka, Griffiths, 2004). However, disclosure is a crucial element prior to eliciting relevant support from employers. Thus, there is a need for informing survivors of their rights in regards to disclose and equipping them with the skills to enable them to communicate this information to their employers so that the latter can respond appropriately to their employees' needs. Relevant psychological services could shoulder this task in order to assist HNC survivors to make an informed decision about disclosure and, if needed, to support them in the process.

6.2.3. Changes in the workplace

This study indicated that the employers' response to employees with HNC could render the reintegration back to work either a positive experience or a negative one. Regrettably, in some cases, the employers were the cause for an unsuccessful attempt for few employees to return to work. In order HNC patients to have a better chance to receive suitable and adequate support from their employers during treatment but also upon return to work, it is important that the latter have an in depth and coherent understanding of the condition, its treatment and patients' needs. This would enable both patients and line managers to work effectively together to reduce stress and ensure smooth transition back to the workplace. Another possible result of such intervention could be a reduction in the ambivalence of employers to retain at work people with cancer. Yet, a study has already indicated that employers need to be provided with support and resources that can assist them put in place relevant help to facilitate employment and job retention of

employees with cancer (Rondinelli, Robinson, Scheer and Weinstein, 1997; Howe, 1975) and this should also be taken into account. Thus, for example, employers could be informed that by being flexible in regards to working hours and time off in the context of offering a phased return to HNC survivors who come back to work may improve the chances of a successful readjustment to the workplace. This should also be within their interest because if patients returning to work too soon or having to meet demanding and unrealistic expectations may result in poor performance, additional period or sick-leave, absenteeism and in some occasions even resignation. It is thus also very important to keep patients in the pay roll throughout this period in order to alleviate them for this additional burden but also to ensure that they return to work after they have recovered sufficient to perform their duties competently.

In addition, Hakanen and Hietanen (2006) showed that there is a clear need for further social support for cancer survivors from other workplace services such as the occupational health department. A study showed that the quality of occupational rehabilitation for cancer survivors can be improved substantially, especially with regards to communication between occupational physicians and specialists in cancer care (Verbeek, Spelten, Kommeijer and Sprangers, 2003). In addition, others suggested occupational specialists to have in their purview the opportunity to take into account disability issues and with their in-depth understanding of the job demands and assessment of employees' capabilities to communicate the findings to employers in order to make a plan and facilitate successful return to work. (Rondinelli, Robinson, Scheer and Weinstein, 1997; Howe, 1975). The incorporation of such practices within the occupational health department is likely to result in higher return to work rates for HNC survivors.

Furthermore, this study showed that the return of some HNC survivors was facilitated by the support and accommodations from their coworkers. Yet, others felt challenged by their fellow workers response once the condition was disclosed to them. Thus, providing relevant information and educating fellow workers about the condition and possible needs of HNC survivors upon return to work is also another potential area for intervention. This can result in an enhanced awareness, which may affect their attitudes towards employees with history of HNC, reduce stigma and improve solidarity.

For all the aforementioned suggestions within the workplace to be possible however, it is importance that such practices should be within the interest of relevant governmental bodies and be incorporated within current policies. This would result in improvements of services within the workplace such by enriching the role of the line managers, their supervisors, the HR and the occupational health department. In addition, by developing a retention strategy would send a very positive message to employees and result in a positive workplace culture that is inclusive of disability and health care issues. Via these interventions it can be ensured a systematic and coordinated return to work support scheme for HNC survivors.

6.2.4. Upgrades within the NHS

Finally, some changes within the NHS system could assist in the care of HNC survivors and their attempt either to remain at work or return after sufficiently recovery. This study showed that some patients found difficult to deal with the inflexibility of the NHS with regard to their appointments and stressed the extra challenge of having to balance their care along with their other work/life responsibilities. Although, understandably it would be impossible for all clinics to coordinate with each other for every patient, it might be helpful to appoint a care coordinator for each patient who can liaise with the relevant departments and organize appointments as flexibly

as possible. In addition, respondents in this study indicated the need to have some practical support in the identification of the right applications in regards to benefits as well as in the completion process. Thus, it is important that there is a personnel within the NHS familiar with these issues so that they can provide this information along with practical assistance HNC patients, when needed. This is particularly relevant to those patients who are cut off from the payroll.

The upgrades within the NHS can be facilitated by governmental grants to improve current services and facilitate return to work for HNC survivors. This investment will in return serve current governmental plans, which aim to provide optimal health care and support people return to employment. UK government has made commitments to reduce the number of working days lost to ill health and to improve access to vocational rehabilitation services (e.g. physiotherapy, counselling and occupational therapy), which will support people to remain in or return to work. It is of interest that in 2008, the Scottish Government has identified return to work for people living with cancer as a priority. Furthermore, Dame Carol Black's review in 2008 of the health of Britain's working age population recommended a multi-agency and partnership approach to supporting people to remain in or return to work and highlighted the role of line managers, general practitioners and vocational rehabilitation services. Governmental funding to upgrade the NHS services will result into improvements in the workforce and eventually the national economy, as is also cited in Grunfeld and colleagues (2008, p.381) and Liu (2007, p.1931). This economic rationale can justify the introduction and application of initiatives from the UK government that could have both individual and societal benefits.

6.3 LIMITATIONS OF THE STUDY AND IMPLICATIONS FOR FUTURE RESEARCH

This study had several limitations that need to be acknowledged so that its findings can be interpreted in context.

The study aimed to understand the experience of HNC survivors only, thus its findings cannot be generalized for other cancer groups. However, given the limited knowledge about HNC patients' experience in regards to return to work, this study contributes to the scientific understanding of this clinical group.

Information was collected four weeks and 12 months after treatment. This is both a strength and limitation of the present study. Taking a longitudinal perspective has revealed important aspects of the process of adjustment to work, and indeed life, following recovery. Conversely, future research on HNC survivors' experiences in regards to return to work might focus on fewer participants and explore the process at more frequent intervals, both during and beyond the first year.

The experience of survivors recruited from a London hospital, especially due to their relatively advantaged educational and socioeconomic profile may not be representative of cancer survivors nationally. In addition, the sample of this study mainly represents respondents who were employed by large companies and thus the results might not reflect the experiences of people who work in medium-sized or smaller organizations or those who are self-employed. It is likely that these employees may have more generous sick leave policies as well as higher wages. Furthermore, most respondents had undertaken higher education and worked in white collar occupations compared with the population of the UK as a whole. Finally, the study included 47 interviews of HNC survivors at four weeks after their treatment

and 32 twelve months onwards, thus any generalizations about experiences of returning to work need to be made with caution. This is because there are numerous reasons and factors, which may influence people's thoughts and decisions about work after cancer diagnosis. The present study provides key themes which might inform future quantitative studies involving large number of HNC survivors across the UK.

A further limitation of the present research was that the qualitative analysis was conducted by a researcher who did not carry out the interviews – though this is perhaps less of a limitation with thematic analysis than some other qualitative methods. To offset this, the immersion phase in the present study was rigorously applied, and the study has a relatively high number of participants, providing a strong sample of experience from which to work. Also, reliability checks involving a member of the original research team showed high consistency. Also, the interview questions were used as guidance to explore patients' experience in regards to return to work. It is likely, however, that this approach might have missed some other topics, which may have been relevant to this study's purpose. However, to ensure that the chosen themes were as closely relevant to this study's aim as possible a thorough review of previous research findings had taken place along with extended discussion with health psychologists in order to define the topics for the respondents' experiences.

Also, some respondents were interviewed via telephone and this could be considered a potential limitation because of the lack of non-verbal communication and the lack of opportunity for the interviewer to build up a rapport with the interviewee. However, anecdotal accounts from the interviewers did not raise concerns of such issues. Furthermore, the duration of the interview for those who attended the clinic in comparison to those who were interviewed by telephone was approximately the same indicating

that all respondents had the same amount of time to express their views. Finally, a number of studies have demonstrated that the use of telephone interviews is a satisfactory research method (Thewes, Butow, Girgis, Pendlebury, 2004; Bradley, Neumark, Luo, Bednarek, Schenk, 2005, Bradley, Oberst, Schenk, 2006; Bouknight, Bradley, Lou, 2006).

Further, this project followed a qualitative approach, which allowed an in-depth exploration of the key issues around return to work for HNC survivors as most studies so far used quantitative methods for their investigations. Yet, its findings and their interpretability could have been strengthened by the support of quantitative data (e.g. using quality of life questionnaires), which could allow the use of mixed methods to analyze the data and lead to more robust conclusions.

Whilst it was not an aim of the present research, future research might gather data from employers alongside their employees. This would provide valuable information in its own right, and also might further contextualize the cancer survivors experience – for example, how does employers understanding and emotional and practical support map on to survivor experience. This is in line with a study which showed that line managers face challenges in managing people with cancer because they lacked support and guidance from senior management (Amir, Wynn, Whitaker and Luker, 2009), which would have allowed them to put in practice the relevant policy. Furthermore, a survey study of occupational health advisers found that the latter report a lack of line managers' understanding about the nature of the occupational health advice being sought regarding employees with history of cancer (Amir et al, 2009). This may explain why some employers appear unwilling to provide the necessary support to their employees. Further research can examine the difficulties employers are facing when managing employees' with history of cancer and assist in the development of

evidence-based guidance regarding the nature of advice they need and the kind of support which would be helpful to provide in order to facilitate the process of their employees' to return to work. This information can be incorporated into current policies to ensure better transition back to work for their employees with history of cancer. Other studies can explore ways to improve communication between line managers, their senior management and the occupational health advisers. Finally, research so far has showed that organisations aim to be supportive of cancer survivors who return to employment and they offer a range of return to work services (Grunfeld et al, 2008, 2010; Kennedy et al, 2007, Pryce et al, 2007). Thus, more in-depth research exploring the employers and occupational health professionals' quality of services provided might shed further light into what kind of updates might improve current practices.

With regard to the broader research process, the findings of this study illustrated the particular issues that HNC survivors face within a year upon return to employment. This work shed light on some factors that need to be addressed in order to facilitate return to work in HNC survivor in particular and provided a list of potential applications (e.g. additions in healthcare professional's duties, psychological input, changes in the workplace and NHS's upgrades), which may improve the provision of current services to ease the return to work experience. Findings from the current study identified possible areas of interest for future studies and can inform their process. For example, there is need for longitudinal quantitative studies to look for predictors and outcomes when cancer survivors attempt to return to employment in order to develop models and inform interventions. More specifically, studies can employ measures that assess quality of life, self-efficacy, emotional and physical wellbeing as well as cognitive functioning at different timepoints.

A systematic literature review by Mehnert (2011) showed that cancer survivors had a significantly increased risk for early retirement and were less likely to be re-employed. The review showed that over a 72-month period post diagnosis 26% to 53% of cancer survivors lost their job or quit working. Therefore, studies can investigate whether head and neck cancer survivors manage to maintain their position in the labour market as they approach retirement age and whether they face more often early retirement on ill health grounds. This is important given the finding that HNC survivors have higher adjusted risk of disability or quitting work in comparison to other cancer types (Spelten et al, 2002; Short et al, 2005) which is usually linked to physical (e.g. ability to speak, Schraub et al, 1995; disfigurement, List et al, 1999) and emotional distress (e.g. anxiety, Schraub et al, 1995) as well as patients' (e.g. age) and work characteristics (e.g. physical demanding job). A larger patient sample could assist in examining in more detail these issues. Moreover, experts in the field have already identified the need for rigorous research of physical and vocational rehabilitation interventions that might improve the health of cancer survivors (Ganz, 1990) and thus it would be useful to extent this research for longer term interventions to examine whether they can improve retention at work. In particular, findings from the present study indicated that psychological interventions could target not only the symptoms experienced by patients but also beliefs and expectations about their ability to work as well as their concerns (and perhaps some misconceptions) about disclosure and eliciting emotional and practical support from their employers. These interventions could facilitate return and retention at the workplace. However, de Boer et al (1999) concluded that the types of treatment HNC patients receive are related to their rehabilitation outcomes and quality of life. Therefore, it would be even more important to intensify research to improve current cancer treatment regimes as they result into serious and

persistent late effects both physical and psychological and thus limit the ability of some survivors to work.

6.4 CONCLUSION

In conclusion, this study produced a rich and varied account of the experience of HNC survivors who return to employment following treatment. The variations found between patients' accounts indicated the role of cancer-related late effects and their interaction with structural environmental aspects such as support from the health care system and their workplace. Based on these insights suggestions for potential interventions were introduced to upgrade the current vocational rehabilitation system and assist cancer survivors to their journey back to employment and to a productive work life. This is particularly relevant given the increased survival figures of HNC patients who return to work, which has significant implications in the workforce and economy. Therefore, these suggestions could be a valuable source of information to assist UK government's undertaking in providing optimal health care and support people with health problems return to employment. The limitations of the present study, although not sufficient enough to undermine findings, support future research designs aiming to investigate more in-depth the experience of return to work and facilitate its process for HNC survivors.

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APPENDICES

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Factors influencing return to work among cancer patients

Information Sheet (Version 1.2) 07.12.05

LREC Study Number: 05/Q0706/178

You are being invited to take part in a research study. Before you decide, it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information about it. Take time to decide whether or not you would like to take part.

About the study

The purpose of this study is to find out about your experiences of either returning to work, or reasons for not returning to work, following your treatment for cancer. We hope to use the results of this study to develop and improve the information that we give to patients following treatment for cancer.

What will the study involve?

You have been asked to participate because you were working prior to your cancer diagnosis and you attended for treatment at King's College Hospital, St Thomas' Hospital, Guy's Hospital, Charing Cross Hospital or Hammersmith Hospital. We will be asking about 500 patients to tell us about their experiences and we are interested in involving people regardless of whether or not they plan to return to work. The reason for this is that we would like to obtain information from a large number of cancer patients many of whom will have different views about returning to work. The study will involve an interview with a researcher, where you will be asked tell us about your experiences. The interview will last about 20 minutes. At this time you will also be asked to complete a questionnaire. The questionnaire will focus on your beliefs about returning to work, illness beliefs and your experiences of symptoms. The interview and questionnaire can either be completed at Guy's hospital, a convenient location for you or over the telephone. If the interview is over the phone you will be sent the questionnaire to complete at home and then send back to us. We would then ask you to complete two further questionnaires, one six months later and one 12 months later. The two further questionnaires will be mailed to your home and you will be provided with a stamped addressed envelope in which to return the completed questionnaire. With the final 12 month questionnaire we will also contact you to arrange an interview which can take place over the phone or in person. The questionnaires and interviews will enable us to follow your progress over a 12-month period.

Please be assured that all information that is collected about you during the course of the research will be kept strictly confidential. Any information you provide will have your name and address removed so that you cannot be recognised from it.

Additional Information

Please contact us if you are unclear about anything at all or would like some additional information. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

If you have any queries please do not hesitate to contact either
Emma Rooney or Lorna Rixon on 020 7188 9324 or email Emma.Rooney@iop.kcl.ac.uk or Lorna.Rixon@iop.kcl.ac.uk

CONSENT FORM (Version 1.1) 13.01.06

Title of study: **Factors influencing return to work among cancer patients**

Name of researchers: **Emma Rooney & Lorna Rixon**

Please initial box

1. I confirm that I have read and understand the information sheet dated 07.12.05 (Version 1.2) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that sections of any of my medical notes may be looked at by a researcher from King's College Hospital, Guy's or St Thomas Hospital where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐

4. I agree to take part in the above study. ☐

Please provide a contact day time telephone number or e-mail address
_____

_____	_____	_____
Name of Patient	Date	Signature

_____	_____	_____
Name of Person taking consent (if different from researcher)	Date	Signature

Researcher	Date	Signature

Example of Transcript T1

HN 02

PATIENT:	It wasn't just the polyp you know, and I wasn't in any cancer wing or anything like that that gave me clues, I was really kept in the dark I suppose. And I was released and Doctor Roberts made another appointment to see me. He said, "What I've done Addie", he said "it was cancer". And it was a ((Neuvoblasfoma?)) I think is the term. And it's a very rare condition, only four people in the country a year get it. And it's positioned right at the very top of your nose, in the hollow part of your nose just under your eyebrow. And he said, "I've taken it away, cleaned it up and I think, I'm pretty sure that I've got it all".
INT:	Okay.
PATIENT:	"But with your general health and age I want to make sure about this, so I want you to come in again and we have another clean up and I have another look around". "Well if you think so doctor, blah, blah". A couple of months later I go in, the same sort of thing, in there for two or three days. No consequences, no bruising, no stitches, no scarring nothing, it's all done by endoscopic surgery. And I couldn't believe how clear my nose was.
INT:	Yeah.
PATIENT:	Then he said, "I think come the New Year, after about eight weeks we need to have you in for Radiotherapy", he said, "because I want to absolutely be belt and braces //…
INT:	Yeah.
PATIENT:	//…about this whole thing and clear it up".
INT:	Yeah.
PATIENT:	And so I had six weeks of that. And during that time you go all through that redness and soreness and puffiness and things. And that's all settled down. Once again I still didn't take any Paracetamol or anything like that.
INT:	Gosh.
PATIENT:	And I think I've been very, very lucky. And he seemed pretty sure in himself and certain with me. Because he is a pretty straight talking fellow, not giving you any flannel.
INT:	Yeah.
PATIENT:	But he thinks he's got it all.
INT:	Good.
PATIENT:	And this Radiotherapy was a clearing up of the area in general just in case anything wanted to come back.
INT:	Yeah. Sure.
PATIENT:	What was your name again, sorry?
INT:	Lorna.
PATIENT:	Lorna?
INT:	Yeah.
PATIENT:	And Lorna that's about it. I haven't got any after effects or symptoms, no nausea, no swelling or bleeding or anything like that, it's just that //…
INT:	That's great.
PATIENT:	//…I'm still getting this little bit of congestion but I just suspect that that's still rubbish to be, I don't know, expected.
INT:	Yeah. So did you work through your treatment?
PATIENT:	Absolutely yeah.
INT:	Really, all the way through?

PATIENT: Yes. Because I had no symptoms, I didn't have any headaches or bruising or anything like that. I felt fine in myself, have done all the way through.
INT: So are you working the same number of hours as you did before?
PATIENT: Not quite as much because the Radiotherapy cut into that //…
INT: Yeah.
PATIENT: // …because of the different times of the day.
INT: Yeah.
PATIENT: But after that obviously I didn't fancy going to work after that too much, so that //…
INT: No of course.
PATIENT: //…pretty much ended the day, the working day.
INT: Yeah sure.
PATIENT: I didn't put any extra in, I ((02:42?)) I just plodded on.
INT: Yeah. Gosh. Okay. So how did you… did you just expect that you would continue with work?
PATIENT: Yeah, I suppose in my naivety and trying to put anything that's not very pleasant to the back of my mind, I just thought I'd carry on indestructible and all that sort of rubbish. But I really seriously haven't had any //…
INT: Difficulties.
PATIENT: //… after effects or difficulties or discomfort in here at all. As I say, they kept… because they said at the end of your treatment is when all your symptoms will accumulate and that's when you'll feel at your lowest and your worst and he said you may feel like a week or ten days holiday to recover/recuperate.
INT: After the Radiotherapy?
PATIENT: Yes.
INT: Yeah.
PATIENT: So I arranged to do that with my family because they've got a place abroad and I went away //…
INT: Nice, yeah.
PATIENT: //…and they gave me packets and packets of Paracetamol and other sorts of painkillers and things //…
INT: Yeah.
PATIENT: //…and I was thinking 'This isn't going to be very pleasant'. And I haven't taken one of them, I've been fine.
INT: Really?
PATIENT: Yeah.
INT: Good, I'm glad to hear that. Now did you tell your employer that you had cancer? Did you have to tell them?
PATIENT: I'm self employed.
INT: Self employed, sorry. Have you… I guess you haven't really needed to tell anybody at work?
PATIENT: No.
INT: No, no. Have you been given any advice or information or support about returning to work or…?
PATIENT: No because I just did.
INT: You just did it?
PATIENT: Yeah.
INT: Do you feel that you're able to work the same hours now //…
PATIENT: Yes.
INT: //…as you did before? Yeah?
PATIENT: Yeah. Over the 37 years I've fell out of love with the job, if you know what I mean. I don't enjoy being there as much as I did. I don't know if it's an ageing process or just getting bored with the job but I don't work as many hours as I used to.
INT: Yeah.
PATIENT: It's not as if ((04:29?))
INT: Have your perspective changed on what's important in life at all after having…?

PATIENT: I guess so yeah.
INT: Yeah. Before you had your cancer how did you view work, was it a positive or negative experience?
PATIENT: It was becoming negative.
INT: It was becoming negative beforehand?
PATIENT: ((04:45?)).
INT: Yeah, okay. So do you feel that work is an important aspect of your life at all?
PATIENT: I would love to stop tomorrow, but I think like everybody else once you've sat around for two weeks you're thinking 'What can I do to pass the time and what hobbies have I got to find myself' and all that sort of thing…
INT: Yeah, sure.
PATIENT: But at the moment work is a negative. I'd much rather not go but in my situation I absolutely and definitely have to.
INT: Yeah. Sure. Do you have any… are you looking to the future at the moment?
PATIENT: Not particularly no.
INT: No? You don't have any goals?
PATIENT: No.
INT: Career.
PATIENT: That's why I'm a London Taxi driver because I have absolutely no ambition. It's been beaten out of me by my family I think who are all very ambitious.
INT: Who are all very ambitious?
PATIENT: Yeah.
INT: Really? Okay. So you've…?
PATIENT: I seem to have, not fought against it, but gone on the other side, see them driving themselves crazy trying to get on and do this and that.
INT: Yeah.
PATIENT: And I've just //…
INT: More laid back.
PATIENT: //…muddled my way through really.
INT: Yeah.
PATIENT: I'd rather go on ten weeks holiday than go and, I don't know, put it into a pension fund or something like that.
INT: Yeah. So do you have any other goals that you'd like to achieve?
PATIENT: Not really no.
INT: Yeah. You're just happy?
PATIENT: Just toddle on.
INT: Yeah. Okay. Well thanks ever so much for helping us.
PATIENT: Is that it?
INT: Yeah. That's it.
PATIENT: Right then. Because I've got unusual circumstances in as much as I'm not asking for any sort of support, I don't need any support, and I haven't got any consequences to the surgery that I had, I suppose I'm different in that way that…
INT: Yeah.
PATIENT: Don't apply to your //…
INT: Oh no it has…
PATIENT: //…survey do I?
INT: No it has been helpful. It's good to get people from a variety of backgrounds, because we'd like to apply what we find to help a variety of people, not just…

Audio ends

Example of Transcript T2

HN04

INT:	… employers been with you since … have they been fine? I presume you haven't actually had to take much time off in total?
PATIENT:	No I only had to take time off around the time of the actual operation. The only thing that I have deemed it necessary to do is basically not tell my employer when I need to go into these appointments. I'm fortunate enough that I live and I work within five minutes of St. Thomas's, so I can basically just shoot across, and then come back before I'm missed. Because I'm met with well I guess you could say a misunderstanding masquerading as hostility.
INT:	Right.
PATIENT:	So a lot of it's just basically not very sympathetic in essence. It's like with a lot of things there's an initial period of sympathy while you'll undergoing treatment and …
INT:	And now it's …
PATIENT:	… things like that.
INT:	… disappeared.
PATIENT:	… going back for follow-ups like there's no they don't think there's much credibility in that whereas, obviously, that's, obviously, the key to ensure there's no …
INT:	Reoccurrence.
PATIENT:	… reoccurrence. So it's just I mean basically I'd have to go cap in hand and beg for a favour every time I needed to go.
INT:	How annoying.
PATIENT:	Well it is but then the flip side is that because I work so close then it means …
INT:	That's just lucky say that you didn't?
PATIENT:	I know I'm very …
INT:	What would you do then?
PATIENT:	… I've mentioned to this to the doctors, I've come down with a very convenient condition which enables me to pop in and pop out. But I think the danger would be …
INT:	It's not really good enough is it?
PATIENT:	It's not good enough at all. If I had to travel I think the danger would be that I would just …
INT:	Lose money or feel uncomfortable.
PATIENT:	Well yeah and the thing they really do, as I say, it would come down to a toss up between either losing money, being subjected to unreasonable …
INT:	Asking for favours.
PATIENT:	… interrogation or, like I say, basically not going which, obviously, as time goes on and as nothing gets found you would start to weigh up well it is really worth causing this amount of aggro at work.
INT:	When you know it's quite important to attend follow-ups isn't it?
PATIENT:	Well yeah I do, obviously, I know that but then it's like a lot of things that you still try to justify it in your own mind that maybe it's like …
INT:	Hassle versus …
PATIENT:	… not going to the dentist, you're supposed to go every six months, but then sometimes you leave it for nine months, and think it can't be that bad. And it's just like that you can convince yourself to put it off for a little bit. But it just doesn't work like that. But, as I say, I'm lucky that I haven't been faced with that decision.

But I could certainly envisage being on the horns of a dilemma nothing to do with, if anything definitely I'd rate my boss as unsympathetic, if not obstructive when it came to that. And it's just extremely ((fortunate?)).

INT: Why do you think that is? Is he not a very nice person?

PATIENT: I don't know.

INT: Is he just clueless about cancer or what?

PATIENT: Well no this is the … no you could say that but then, obviously, you glean bits of information, when you realise that their family members have also been affected by cancer. So it's I don't know, you could call it callousness, you could call it male I don't know, bravado, just a different kind of … a very you could say like 1970's style …

INT: Gosh.

PATIENT: … doesn't quite match up with the current legislation in regards to what legal rights that you have. And maybe you can say that in the contract it will say that you have these legal rights, but then you'll lose all your benefits or be subjected to humiliating interrogation in an open plan office as to say what was "So you're not dying then" and things like that. Whereas, obviously, no one should, obviously, be subjected to stuff like that, especially when you haven't really got … because it's all to do with the power balance that you can't really just turn around and tell your boss to eff off.

INT: No.

PATIENT: Whereas you could do that to a colleague. You could be quite sharp with a colleague, whereas with a boss you have to weigh up the implications of what you're saying.

INT: So is it just his decision? Do you think it would be better if there was more than one person involved do you think it would be fairer?

PATIENT: I don't know. Maybe part of it is the fact that where I work there's no independent personnel department, so you don't have that right of appeal or to go to someone whose job it is to ensure that your rights are respected. You're having to deal with the person who's supervising …

INT: Wants the job done.

PATIENT: Who wants the job done and wants everything else done and that's his bottom line. And so anything you say to the contrary is going to be getting him in trouble …

INT: Conflict.

PATIENT: … yeah. So I think, obviously, the law is heading in the right direction but then, obviously, the other trade off is it's sometimes if it's something personal you don't want to necessarily have to send a memo round and bring in everyone in on the decision making.

INT: "Hi everyone, I've got cancer."

PATIENT: Well yeah that's the thing. I've managed to restrict the information to five people at work. And that was the absolute … seemed to be the absolute minimum, because obviously, you've got your line manager, their manager then the secretary, and then two of my colleagues. But I can't say how many people they may have elected to choose to tell. But I made it expressly clear that if anyone came up to me, anyone who wasn't of those five, I'd do my best to retaliate. But once the information's out there there's not a lot you can do.

INT: No.

PATIENT: So I don't know, I don't know what the solution ideally is. I think …

INT: In terms how we could make it easier for other people?

PATIENT: Yeah I think some kind of, like I say, independent yet in-house independent personnel department. Or just even maybe it would require something to be enshrined in law that …

INT: Maybe a checklist of things that employer's could do …

PATIENT: Yeah.

INT: … that can be taken from the hospital or something?

PATIENT: Yeah just something yeah like some kind of more …

INT: So that you don't have to feel uncomfortable asking for it.

PATIENT: Yes so these are your rights and things like that. Because a lot of the times whenever I've gone to appointments and explained about the situation then I'm always met with surprise and indignation and "Oh that's terrible." But then, ultimately, not much …

INT: We can do about it.

PATIENT: … not much they can do about it and whether I'd want them to interfere I don't know. But at least if you had the ammunition yourself to say, "This is the situation, these are my rights" and it may well come down to having to be informed of your rights in the hospital. While, obviously, it's very easy to pass that back to some department that works on pensions and say the information is available, but to be informed what your employer's obligations are at the point of … at the hospital, that might be helpful so you didn't have to go looking up the information, if you could be presented with it as part of your pack of these are the things that you're going to have to deal with and so be aware that these are your …

INT: And this is what other people have found helpful.

PATIENT: Well yeah. So that's just an idea. But, obviously, it's difficult to say, like I say, every situation's different.

INT: Sure.

PATIENT: And they've all got their own little quirks of management.

INT: In terms of getting back to work is there anything that you would've done differently, or are you happy with how …

PATIENT: No I think I'm happy with how it all worked. Yeah even I took things easy yet still wanted to feel like I was doing … I didn't want to be molly coddled, and feel that I had to be accompanied wherever I went in case I collapsed. But no I think I got back in, I was keen to get back to work just because I felt that that was … occupational therapy would be the best way to get back into the swing of things, because I have a physical job. So it meant that I didn't have to ((10:22?)) …

INT: A bit of distraction?

PATIENT: … to exercise I was just doing it through work.

INT: Okay. So you would say that your intentions in terms of returning to work have been achieved?

PATIENT: Yeah.

INT: Yeah. Okay, great. Do you have any advice to people wanting to go back to work from what you've been through? Is there anything, if you could say something to … you might not, but if someone was in a 12 months … how you were 12 months ago, is there anything that you would think to warn them about or anything that's been particularly helpful for you?

PATIENT: No I suppose the one thing that kind of shocked me was the extent of the scarring after the operation.

INT: Yeah you weren't expecting that?

PATIENT: No I was a bit taken aback. Just because, obviously, the scars you tend to pick up through just day to day activities tend to be quite light and narrow, whereas the kind of scars that I got after the operation were, obviously, quite …

INT: More extensive.

PATIENT: … more extensive - wide and long. But I suppose the fact that you do get better, scars do heal up.

INT: Did you feel a bit self conscious?

PATIENT: Yeah and the only thing that I did … it was actually quite a struggle to get assistance with post-operative scar tissue …

INT: Care.

PATIENT: … therapy I suppose. Yeah I've got this Dermatix stuff which I found out about several …

INT: Quite a bit later.

PATIENT: … months later ((12:34?)) told about at the time. Vague promises were made about laser therapy and steroid injections, and it took a hell of a lot of persistence to get

one steroid injection and nothing else subsequently. So that was the only thing, it seemed to be that it was a real uphill battle to …

INT: To get any …

PATIENT: … get any help when it was made, as I say, it was basically like a false assurance that was made, that it was all part of the programme. You have the operation and then the next stage is to deal with the scar. Whereas it seems to be you have the operation and then …

INT: It's more geared at surviving.

PATIENT: More geared at surviving, which I guess is fair enough. Obviously, they've got their priorities right but that's their priorities …

INT: In addition.

PATIENT: … whereas at the time my priorities are basically trying to fit in again. And having a huge purple scar was an obstacle to that.

INT: How have you dealt with that? Do you say anything to anyone or do you just ignore it?

PATIENT: Most people don't really say anything. I'm lucky the fact that it's running underneath my jaw so it's not the first thing that you see.

INT: No. So it's more you know it's there …

PATIENT: Yeah it's more …

INT: … no one's stared or?

PATIENT: Yeah I'm definitely well I was a lot more self conscious of it than I am now. And now yeah it's not even … no one's actually asked me about it independently. So in that sense it hasn't really been, it was never as bad as what I feared it was. But at the time, obviously, I felt a bit vulnerable and exposed.

INT: Of course yeah.

PATIENT: And so I felt I would've benefitted at least if I was given a timetable. Like after six months we'll do this.

INT: What to expect.

PATIENT: What to expect and in terms of therapy and things like that, so I'd have something to look forward to. And, like I said, not being told about the Dermatix until way later, it felt like it was definitely …

INT: Much later than ideal.

PATIENT: … down to me. Yeah. I think it would've helped to have a bit more of scheduled aftercare instead of it being down to me to force the issue.

INT: Sure.

PATIENT: But that would be the only thing I could think that it could've been done better.

INT: Yeah.

PATIENT: But yeah that's about it.

INT: Yeah. Sure. Okay that's great. Would you have liked to have received further information about returning to work specifically? Or information about … sorry and if so, how would you like to receive this information? So leaflet, internet, face to face I don't know whether you would've found anything like that useful?

PATIENT: Probably leaflet although the one thing I could say about that was that the because of the nature of the operation I had, I'd had some lymph nodes removed from my neck, there wasn't actually any appropriate information available for physiotherapy I could do at home, so I made do with a … if you had a mastectomy. And that was the nearest thing that they had. I don't know if that's wrong it seemed to do the trick. But it would be good if they could get the initial paperwork sorted before they embarked upon anything else. But, like I say, I still say when it came to coming back to work about knowing your rights and knowing what your entitlement is.

INT: Would you say like a good … you don't want to give people information too quickly because, in a sense, it seems insensitive to start talking about return to work too early on, but then you don't want to leave people worrying about it.

PATIENT: Yeah it depends what kind of state you're in really. I had my eye on returning to work, and wanted to get well and up to speed as soon as possible. So I don't know I

	think to be presented with the information so then you can make your own long term plans would be beneficial. Yeah I guess it's difficult to say that you don't want to feel that you're hurrying people along.
INT:	No, sure.
PATIENT:	But then also you don't want to feel that information's being withheld from you until the right moment. Well that's how I would feel. I'd want to know it all, so then I could make my own mind up not be drip fed information.
INT:	So you're in control of the speed in which you receive the information.
PATIENT:	That's me. That's important for me to have all the information to hand.
INT:	Yeah I'm sure you're not alone there. Okay. Last couple of questions, I said it wouldn't take long didn't I ((18:20?)) managed to chatter on.
PATIENT:	I think I've done most of the talking.
INT:	Yeah. So are you still feeling that work is enjoyable, important …
PATIENT:	Yeah.
INT:	… as much as you ever did?
PATIENT:	Yeah.
INT:	Yeah. And if you had any career goals or goals outside of work have you made any steps in achieving them?
PATIENT:	Yeah basically just carried on doing what I want to do and making things better bit by bit. So yeah I wouldn't say it's … yeah it hasn't held me back. I was actually fortunate I managed to schedule some of the initial treatments around my pre-existing plans. So that was fortunate that I did that so I didn't feel like I was jeopardising …
INT:	Anything yeah.
PATIENT:	… anything. So I was lucky …
INT:	That's great.
PATIENT:	… that I could say I don't want to you to treat me then, I want you to treat me then, and they managed to fit in around that. So that's yeah quite a liberty.
INT:	Great. Okay. Yeah that's the end of my questions. Do you have anything to add, or do you think I've covered everything?
PATIENT:	No I think you've covered, obviously, I don't know what the ultimate outcome of your …

Audio Ends

T1 - List of Themes with Examples

T2 - List of Themes with Examples

T1-T2 - List of and emerged theme at T1 and T2 with Example

Service Evaluation Project

THE EVALUATION OF A THREE DAYS PROGRAMME FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

Supervisor: Dr Patrick Smith

ABSTRACT

Children with autism spectrum disorder (ASD) have pervasive and enduring difficulties and represent a challenge for their parents. The latter are likely to look for interventions which can assist them to manage more effectively their children's difficulties. Literature has shown that parental role is influential in early intervention for children with ASD. Therefore, many programmes have been developed with an educational character to provide parents with the required information. A three day programme is offered by the Autism and Related Disorders team at the Michael Rutter Centre at the Maudsley Hospital to educate parents of ASD children. The present project aimed to evaluate the effectiveness of this programme. Parents representing 15 children with ASD completed the Autism Parent Questionnaire (APQ) which measures parental behaviour at the beginning and at the end of the three day programme. Results indicated positive outcomes for parents following their participation in the programme. In addition, parents made suggestions as to how the programme could evolve to incorporate more behaviour management advice for specific behavioural difficulties that they face with their child. Implications of the present study are discussed and directions for future evaluative studies are presented.

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LIST OF TABLES

INTRODUCTION

This section presents information with regard to the service where the present evaluation took place. It introduces autism spectrum disorders (ASD) and describes their different variations. Information is provided with regard to prevalence, gender differences and aetiology. The various therapeutic options available in ASD are discussed with an emphasis on the parent focused interventions. Finally, the aim and hypothesis of this project are presented.

1.1. The service

The National and Specialist Child and Adolescent Mental Health Services within the South London and Maudsley NHS Foundation Trust include an outpatient department at the Maudsley Hospital based at the Michael Rutter Centre. One of its services, called the Child and Adolescent Autism and Related Disorders Service, offers assessment and treatment for children and adolescents with autism, pervasive developmental disorders and related difficulties such as Williams syndrome, Prader-Willi syndrome and Down's syndrome. The service specialises in diagnosing and managing individuals with autism and related disorders (ARD) who also present challenging behavioural and psychiatric problems. The offerings of this service are provided through Clinical Academic Groups which ensures that the latest research findings on improved care and treatment are provided by bringing together clinical services, research, education and training. The team consists of psychiatrists, clinical psychologists and a mental health worker. Consultant psychiatrists, consultant paediatricians and GPs can refer to this service children and adolescents up to 18 years old, male or female with either a known or a possible diagnosis or ARD. Interventions of the service include assessment using standardised measures of IQ, language ability and other cognitive functions as well as emotional and behavioural difficulties

and feedback of the results to the relevant parties. In addition, genetic counselling, individual counselling, cognitive behavioural therapy, social skills training, behavioural management advice to schools and families, and educational advice are also offered within this department. Finally, the service provides information, advice and consultation to caregivers in order to manage more effectively children or young people with ARD.

1.2. On autism spectrum disorders

Historically, autism was identified in 1943 when Kanner (1943, cited in Kanner, 1973) categorised a group of children whom he described as displaying social aloofness, an indifference to others, and repetitive stereotyped play (autism) while Asperger (1944) described children with high intellectual ability and precocious language (Asperger's syndrome) as well as children with low ability and poor language (autism spectrum).

Nowadays, autism spectrum disorders are also known as pervasive developmental disorders because they involve delay in many areas of development. They are characterised by qualitative impairments in verbal and nonverbal communication, poor social interaction, and restricted or stereotyped patterns of behaviours, interests and activities. These deficits are describes as the "triad of impairments" (Wing and Gould, 1979). Moreover, the perceptual, attentional and sensory processes of individuals with ASD differ. For example, they often have abnormal reactions to sensory stimuli including noise and physical touch (Gillberg and Coleman, 2000; Rogers, Hepburn and Wehner, 2003). Finally, the presentation of symptoms is different from case to case and they also tend to change over time, as do expectations for typical behaviour.

Among the group of ASD, autism is best understood so far; the other disorders in the group are seen as less extreme variations on the same

theme. A child must display the aforementioned difficulties prior to 36 months in order to be diagnosed with autism (DSM-IV; American Psychiatric Association, 2000), yet its symptoms are more evident in childhood and persist into adulthood. Asperger's syndrome (AS) is along the continuum of ASD. Although the social communication deficits are similar between individuals with AS and autism, their cognitive development and adaptive skills differ, in that there is no significant delays is AS. For example, the main difference between the two conditions which assist in diagnosis is that in AS early language development is normal. In addition, the obsessions in AS are more associated with special interests, rather than specific behaviours as is often the case in autism (DSM-IV; American Psychiatric Association, 2000). High-functioning autism (HFA) is another condition within the group of Autism Spectrum Disorders, where individuals have language delay but IQ within the normal range. In addition, a number of studies suggest that individuals with HFA have poor "theory of mind" meaning that their ability to understand that others' mental states, beliefs and feelings may differ from one's own is limited (Ozonoff and Miller, 1995; Szatmari, Archer, Fisman, Streiner and Wilson, 1995).

The prevalence of autism is about 1 in 1,000 (MRC Research Review in autism, 2001) whereas estimates of AS around 2 per 10,000 (Baird, Simonoff, Pickles, Chalnder, Loucas, Meldrum and Charman, 2006). Although, it is likely that the prevalence rates may increase in due course, due to the broadening of diagnostic definitions or increased awareness.

Males are three times more likely to be diagnosed with autism in comparison to females and four times more likely to have AS (Lord and Schopler, 1985; Baird et al, 2006; Fombonne and Tidmarsh, 2003). However,

the gender differences are less pronounced at the high-ability end of the spectrum (MRC Research Review of autism, 2001).

Despite continuing research over the years, the exact aetiology of autism remains unknown. An early theory (Bettelheim, 1967) attributed autism to the parenting deficits of a cold and unloving mother but was later discredited as it did not stand up to empirical investigation (e.g. Cantwell, Rutter, and Baker, 1978). Current theories focus around evidence which suggest that a polygenetically determined predisposition is subsequently overlaid with a variable and unknown combination of organic and environmental insults (Rutter, Bailey, Bolton, and Le Couteur, 1994). These insults potentially involve prenatal or perinatal complications (Carr, 1999), elevation of blood serotonin, dopamine system impairments, viral infections, and immune dysfunction (Frith, 1989).

Yet, what is known so far is the fact that the nature of difficulties for individuals with ASD is pervasive and enduring. Therefore, it comes as no surprise that children with ASD can represent a challenge to their families and are likely to need interventions throughout their lives.

1.3. Therapeutic interventions in ASD

Over the years a number of different treatments for ASD have been suggested, however, these approaches have been criticised for their effectiveness. In this section, a selected few of these interventions are presented as examples. Emphasis is placed on early intervention studies and, in particular, parent-focused programmes, which have better evidence of their effectiveness and which also provided the theoretical rationale for the present study.

It was suggested that sensitivity to sound which can lead to behavioural difficulties in autism may be the result of hearing distortions; thus treatment involves the use of filters to eliminate these peaks via an Auditory Integration Training (AIT; Berard, 2000). Yet, Beaulieu, Tweed and Connolly, 2009) in their review reported that all studies but one found that AIT had no impact on autistic behaviour and concluded that there is need for further high-quality controlled studies in order to determine if there is any merit to AIT. Changes in the diet regime of children with ASD have often been suggested as a means of intervention to reduce behavioural disturbances. For example, Bidet, Leboyer, Descours, Bouvard and Benveniste, (1993) proposed allergen free diets whilst others suggested vitamin treatments in autism (Raiten and Massaro, 1986; Rimland, 1995). However, in their report Beaulieu and colleagues (2009) argued that studies using diet and nutritional approaches as intervention for ASD provided insufficient to preliminary evidence for their effectiveness. Music therapy is another approach which several researchers have reported to be effective on behavioural problems in autism (e.g. Alvin, 1968; Trevarthen, Aitken, Papoudi and Roberts, 1996, for review). The general principles under which music therapy operates regard the development of a trusting relationship, self-expression and social interaction. Alvin and Warwick (1991) argued that the qualities of musical sound provide children with autism the scene to acquire new experiences of themselves. The same authors presented cases of children across the autistic continuum, with varying degrees of learning difficulties, idiosyncratic and avoidance behaviour and showed that the music therapy process was engaging these children in musical-emotional communication. A review by Gold, Wigram and Elefant (2010) aimed to examine the effects of music therapy for ASD and looked into randomised controlled trials or controlled clinical trials which compared music therapy alone or music therapy added to standard care to placebo therapy, no treatment or standard care. They found that although music therapy was

superior to placebo with regard to verbal and non-verbal communication, no significant effect was found with regard to behavioural problems.

Another approach focuses on early intervention programmes which aim to enhance the development of young children by increasing their opportunities for learning. The rationale behind such interventions lies in the fact that early years is the critical period for learning and that the plasticity of the brain at this age can shape capabilities to compensate for deficits through "cognitive rewiring", which can shape future development (Peterson, 1987). However, although overall early behavioural and educational interventions are considered a good option for children with autism, there is no evidence with regard to approach, level of intensity, degree of structure or even age of onset. For example, Lovaas (1987) found that 9 out of 19 children with autism gained normal functioning after two or more years following an intensive early intervention programme. Yet, his findings fail to be replicated (e.g. Sallow and Graupner, 2005). This conflicting evidence for the effectiveness of early intervention in autism, led Bibby (2002) to note that it is difficult to determine which of the numerous variables in operation in such programmes are the most critical for their efficacy.

Other experts in the field highlighted the importance of involving parents in the early intervention programmes (Godfrey, Moore, and Fletcher-Flinn, 2002; Bronfenbrenner, 1974). The argument was that, by providing them with the required knowledge and skills, parents would be able to consolidate the effects of such programmes by knowing how to reinforce their child's learning and development. This argument can stand on theoretical rationales such as the ones put forward by experts in the field. For example, Thart and Wetzel (1969) proposed that parents as the logical agents to bring about change to their child whereas the therapist has a

"consultant" role and the child is the "target". They viewed the parents working collaboratively with the therapist in order to learn how to handle their child and improve behaviour. Another theoretical rational is based on Schopler's (1984) suggestion that the experts on the child are the parents. Schopler acknowledged parents' knowledge of their children and advocated that they should be making the key decision while professionals should act in a supportive manner and offer technical advice. Therefore, the efficacy of parent training can be boosted by the fact that parents spend longer time with their children and can create a consistent home environment for learning. The latter also often desire to be involved in their children's interventions as much as possible in order to manage challenging behaviours and improve their family's functioning (Case-Smith and Arbesman, 2008). In addition, parental programmes could reduce parental stress because parents learn how to manage behavioural problems. Bristol, Gallagher and Holt (1993), for example, found reduced depressive symptoms in mothers who participated in programmes which helped them to understand how to manage their child's learning and behaviour problems more effectively. Furthermore, studies showed that parent's confidence and self-esteem improves following education about autism and behaviour management and can have a positive impact on child's behaviour (Sofronoff & Farbotko, 2002; Sorfonoff, Leslie, & Brown, 2004). A randomised trial found that parents who received education had significant gains in knowledge about autism, increased sense of control and improved satisfaction (Jocelyn, Casiro, Beattie, Bow, & Kneisz, 1998). Finally, another study showed significant improvements in parental mental health following parent education and behaviour management intervention (Tonge, Brereton, Kiomall, Mackinnon, King, Rinehart, 2006).

These lines of thought led to the development of different parent focused programmes. Literature suggests that such programmes are potentially effective.

A review of 24 studies on children aged 3 to 8 years, conducted by Levy, Kim, and Olive (2006), showed that direct parental involvement was among the most effective interventions for children with ASD. It was shown that following training, parents implemented the learned techniques and as a result the speech skills, language development, social interaction, cognitive functioning, and behavior management were significantly increased. McConachie and Diggle (2007) conducted a systematic review on interventions focusing on parents of ASD children aged 1 to 6 years old. They found that parent training including home sessions and practice led to improvements in their children's communication, increased maternal knowledge of autism and reduced depression, and improved parent-child interaction. Furthermore, Frea and Hepburn (1999) assessed two families within controlled case studies and investigated parents' ability to learn functional assessment skills and to design independently interventions. Results showed that that parents learned to perform successfully functional assessments of their child's disruptive behaviours and plan appropriate interventions. Reamer, Brady and Hawkins (1998) used video-based intervention along with self-assessment, self-modeling, discrimination training and behavioural rehearsal on two sets of parents' interactions with their children during self-care tasks and social play with their siblings. Findings indicated that their intervention managed to alter parental interactions with the child. Parents increased their social prompts and altered their assistance during children's tasks. Aldred, Pollard and Adams (2001) used video feedback so that parents can reflect on their own interaction and identify successfully strategies to engage their child. They

introduced play as an effective means to reduce communication impairments.

Encouraging evidence of its effectiveness has been found for another programme called the "Triple P" (Positive Parenting Programme; Sanders and Glynn, 1981). This program was developed using theories included in behavioural family intervention, and its aim was to encourage the independence of families by providing parents with knowledge, skills and confidence to deal with mild or major behavioural problems. It consisted of brief primary care consultations followed by more intensive parent training. The programme used face to face interactions, group interventions, telephone assistance and self-directed modalities to address the family's needs and requirements. Across many studies it was found that child behavioural problems were decreased following parents' training within this programme (Sanders and Dadds, 1993). An extension of this programme called the "Stepping Stones Triple P" is a system developed to specifically address the needs of families who have a child with a disability and help them to manage children behavioural problems and developmental issues more effectively. A randomized controlled trial of fifty-nine families with a child with ASD aged between 2 and 9 showed that after using this system parents reported improved child behaviour and better relationship with their partner. A follow-up 6 months later showed that benefits were maintained. Overall the trial demonstrated that Stepping Stones Triple P is a promising intervention for parents of children with ASD (Whittingham, Sofronoff, Sheffield and Sanders, 2009).

The EarlyBird, developed by Shields, (2001), is another early intervention programme for parents. This programme lasts for three months and offers 8 group training sessions in conjunction with home visits and video feedback. Its aim is to educate parents about autism, as it is based on the premise that

parents' understanding of the condition is required in order to enable them to develop their child's communication and social interaction skills, as well as to learn how to manage their child's difficult behaviours (Shields, 1999). This programme uses a number of approaches, such as services and techniques from the Treatment and Education of Autistic and related Communication handicapped Children approach (TEACCH; Schopler and Mesibov, 1984) which provides parent training and parent support groups as well as information on social play and recreation groups, the Picture Exchange Communication System (PECS; Bondy and Frost, 1994) which uses picture symbols as a mode to increase communication, and the SPELL approach (Siddles, Mills and Collins (1997) which stands for **s**tructure, **p**ositive attitudes and realistic expectations of progress, **e**mpathy for the child, **l**ow arousal learning environment and **l**inks to other parties involved in child's care, and aims to designs environments and a teaching framework to support learning. Hardy (1999) evaluated this programme in a study which involved 30 families; 18 participated in the EarlyBird programme and 12 were non-participants. Findings revealed significant differences in adaptive functioning and showed a reduction in the gap between children's chronological age and developmental level before and after the programme. Significant differences were also found in parental stress and a child's communication level.

Finally, the EarlyBird study carried out in New Zealand was found to be effective based on pre and post analysis of the Autism Parent Questionnaire (APQ), which assesses changes in parental behaviour (Anderson, Birkin, Seymour and Moore, 2006). The APQ was administered together with the Child Autism Rating Scale-Parent Version (CARS-P; Bebko, Konstantareas, & Springer, 1987), which assesses parental perspective of their children's level of functioning. This early intervention programme for parents ran in a

national level for a year and found positive outcomes for the families participating in the study.

1.4. The current project

During recent years, the Child and Adolescent Autism and Related Disorders Service based at the Michael Rutter Centre as part of its services has offered an educational programme called "Learning about Autism" to parents of ASD children which provide information around autism. This is a three day intensive course which runs twice a year for up to 30 attendees. Experts from different fields such as psychiatrists, clinical psychologists and child mental health workers give talks on a number of topics around autism. The rationale behind this programme was that coherent information on ASD from experts could reach more people and each of them could benefit by asking questions relevant to their child and learning from other peoples' stories.

As section 1.3. indicated, parent-focused programmes using psychoeducation within their training schedule has been shown to be an effective evidence-based intervention for children with ASD and thus has attracted a lot of research attention. Therefore, the aim of the present project was to evaluate the "Learning about Autism" programme. The Autism Parent Questionnaire (APQ; Anderson et al, 2006) was administered both at the beginning and at the end of the programme to evaluate its effectiveness by measuring changes in parenting skills.

1.5. Hypothesis:

It was predicted that at the end of the three day course parents would show an improved outcome on the APQ, which would suggest that their parenting skills have improved.

METHODOLOGY

This section describes the design employed for this project and provides information with regard to both the participants who attended the course as well as their children. The measure used to assess changes is described and information is given on its reliability and validity. Finally, details with regard to how the course ran and the study conducted are provided.

2.1. Design

This study employed a repeated-measures design. The Autism Parent Questionnaire was administered at the beginning (T1) and at the end (T2) of the parents' course to measure changes. The dependent variables (DV) were the total score of the APQ and its subscales' scores, whilst the independent variable (IV) was time (i.e. T1 and T2).

2.2. Participants

Parents were informed about the three day programme either from their local clinics or from the Bromley Autistic Trust and were advised to contact the mental health worker of the ARD team if they were interested in attending. Thirty parents were invited to the course. Eventually, twenty-two parents attended representing fifteen children. All participants were parents of at least one child with ASD and had recently received a diagnosis for their child. Table 1 shows the children's age. All children were boys.

Table 1: Number of children represented and their age

N	Range	Mean	SD
15	3-13 years old	7.6	3.019

2.3. Measure

The Autism Parent Questionnaire (APQ) was administered as a pre and post measure to assess each parent's progress following the parent-focused intervention programme, and to evaluate its effectiveness. It was initially developed as part of the NAS EarlyBird programme in New Zealand (Anderson et al, 2006) and was considered the most appropriate measure for this study given the similarity of the two projects' aims, hence the assessment of parental behaviour and the evaluation of the intervention programmes. In addition, it was preferred over other measures such as the CARS-P (Bebko et al, 1987), the Parenting Stress Index (PSI; Abidin, 1995), and the Family Environment Scales (FES; Moos and Moos, 2002) because APQ incorporates a variety of subscales whereas these measures address only one. The APQ is a short, reliable, self-report questionnaire that assesses changes in parental behaviour. It consists of 25 items, scored on a six-point Likert scale ranging from "not true at all" to "definitely true" (See Appendix). It is formed by 7 main components: knowledge about autism, communication - language, play, behaviour management, stress management, and confidence and family functioning (see Table 2). A high score on a given subscale represents favourable parenting behaviours within that specific domain. The total score gives an overall indication of parenting skills in relation to a child with autism with a high score being positive. APQ's internal consistency has been found to be satisfactory both for the subscales and the total score. This provides support for the reliability of the measure. The APQ stress subscale has been found to be significantly correlated with the stress component (part b) of CARS-P (Bebko et al, 1987) providing support for the validity of the APQ stress subscale (Anderson et al, 2006). APQ takes approximately 10 minutes to complete.

Table 2: Description of what the APQ subscales assess

Scale	Description
Knowledge about autism	Parents' understanding of how their children differ from typical children
Communication	Parents' ways of communicating with their child
Play	Parents' use of play to interact with their child and to teach social interaction skills
Behaviour management	Parents' skills to manage their child's behaviour
Confidence	Parents' optimism and confidence in parenting
Stress management	Parental stress based on perception of help available, and the degree to which autism dominates their life and long-term responsibilities
Family functioning	How well the family as a unit is running

2.4. Procedure

The three day parents' course ran at the Michael Rutter Centre at the Maudsley Hospital. The programme ran daily from 9:30am to 3:00pm and had a 15 minute break at 11:15am for coffee and a half an hour break at 12:30pm for lunch. On the first day the topics covered general information on ASD, on benefits and useful agencies/legal rights, and consideration and on education choices. On the second day, there were two talks on strategies for behavioural management and on puberty and sexuality in children with ASD. On the third day, information was given with regards to the genetic origins in autism and information on communication. Talks were given verbally with the use of PowerPoint slides and following completion, participants were invited to ask questions. Participants were also given hardcopies of the presentations. Most topics were suggested by health care professionals working with parents of ASD children based on their experience of what parents usually want to know. Some topics were added following parents' feedback of the three days course in the past. Talks were given by a child mental health worker, a mental health service manager, a consultant clinical psychologist, a clinical and child psychologist, a speech and language therapist and a child and adolescent psychiatrist. The APQ

was administered at the beginning of the first day and at the end of the three day course. Audit approval was given for the conduction of this study.

RESULTS

3.1. Quantitative findings

Participants represented 15 children and completed the APQ both at the beginning and at the end of the three day course. Given the small number of represented children and consequently the number of APQ questionnaires collected, non-parametric tests were used in the analysis, which make no assumptions about the normal distribution of the data.

The median values of the APQ's total score and its subscales are presented according to the pre and post time variables (T1 and T2). Their lower and upper quartiles are shown in brackets. The significant changes as determined by the Wilcoxon signed ranks test are also presented. (Table 3) The Bonferonni correction was employed because multiple analyses were performed. The significance alpha level was set at 0.006 or (0.05/8).

Table 3: Pre and post median scores of all variables along with their lower and upper quartiles and significant changes for the parents' groups who represented 15 children

	Group (n=15)		
	Median (LQ - UQ)		
	T1	T2	Sig.
Subscales			
Total Score	98 (89-111)	116 (98-117)	p =.003*
Knowledge	16 (11-21)	21 (17-22)	p =.002*
Communication	18 (13-20)	19 (19-22)	p =.010
Play	14 (12-15)	15(12-16)	p =.068
Behaviour management	15 (13-18)	19 (15-23)	p =.005*
Stress	12 (10-15)	11 (8-13)	p =.011
Confidence	15 (14-16)	14 (12-16)	p =.560

	Family functioning	13 (11-14)	14 (12-15)	p =.036

*p ≤.006

The Wilcoxon signed ranks test found three significant changes on APQ scores in the parents' group after the end of the three day programme. Based on the APQ's total scores, parents showed a significantly improved overall parental behaviour (Z= -2.928, p = .003). Further analyses of the APQ's subscales also indicated improved significant changes in the "knowledge" (Z= -3.072, p = .002) and "behaviour management" (Z= -2.805, p = .005). These significant changes remained even after the Bonferonni correction.

The "communication", "play", "stress", "confidence" and "family functioning" subscales were also significant at uncorrected alpha level of 0.05. However, following Bonferonni correction these changes did not remain significant.

3.2. Qualitative information

Although the present study did not aim to collect and analyse qualitative information in a systematic way, verbal feedback from participants at the end of the programme provided useful insights.

At the end of the course, participants commented on how valuable they found the programme. They reported that the topics covered were useful and relevant to them and were structured in a comprehensive way. They found the Power Point presentations easy to follow and to understand and did not feel that the information was overwhelming. They said that they valued the fact they were given handouts which they could refer to should they needed to remind themselves information from the program. In particular, they found useful to have written guidance on where to look for further information when needed. Finally, participants said that the time provided to ask questions was an important part of the programme.

Interestingly, however, the group also fed back that they would have found it very useful to have some time within the programme where they could elaborate on specific behavioural problems that they face with their child. They explained that they all have to confront daily a variety of behavioural challenges from their child such as repetitive questioning, difficulties in communication and rigid behaviours, and their limited knowledge on ASD does not help them to address them effectively. Participants said that it would be useful if they could be provided with advice and perhaps material which they could apply themselves as soon as they return home and would assist them to address better their child's specific behavioural challenge. They also said that this could have a positive impact on their own stress levels and overall family functioning. Therefore, although they reported that they felt that they knew more on ASD following the programme, they would still welcome information from the experts on how to address these challenges and manage them more effectively.

DISCUSSION

This project emerged from a service need to evaluate the effectiveness of a three day parent focused programme which is offered by the ARD team at the Michael Rutter Centre at the Maudsley Hospital. The programme aimed to provide information on parents of ASD children around this condition and consisted of talks given by experts in the field. Participants were provided information on a number of topics around ASD such as educational options, legal rights and strategies on behavioural management. This study's aim was to assess changes in parental behaviour based on pre and post analysis of the APQ and evaluate the effectiveness of the course. Parents represented 15 children and they all returned a completed APQ at both points in time.

4.1. Presentation of the results

Findings from the present study showed a significant increase in total APQ scores between pre and post programme times. Results also showed that parents' scores improved in the "knowledge" and "behaviour management" subscales of the APQ following the three day course. The "knowledge" subscale measures parents' understanding of the difference between typical children and children with ASD, and the "behaviour management" subscale measures parental ability to manage their child's behaviour. Given the structure of the three day programme, which provided general information about ASD with an emphasis on common behavioural management strategies, these findings are not surprising. These results suggest that the equivalent factors tapped by the APQ (i.e. Knowledge and behavioural

management) are more direct or immediate outcome measures. Overall, results indicated that participants reported improved parental behaviour by the end of the programme.

All the remaining APQ subscales (i.e. "communication", "play", "stress" and "family functioning"), with the exception of the "confidence" subscale, were also found significant prior to the Bonferonni correction. These findings are in the same direction as Anderson's et al (2006) EarlyBird national study who also found significant pre and post changes in the total score of the APQ and all its subscales apart from the "confidence" one. However, following Bonferroni correction, which was necessary due to multiple analyses, these significant changes disappeared. A possible explanation of this could be that parents need to take some time to integrate into their daily routine the new information and skills. This is particularly relevant in the context that these subscales may represent an indirect outcome, and it is likely that positive effects may show only after some time.

Overall, the findings of the present project echo results from previous studies which assessed educational programmes for parents of ASD children (e.g. Sanders and Glynn, 1981; Shields, 2001, Anderson et al, 2006). These results also provide further evidence to the notion that parental involvements in early intervention programmes is a crucial element (Godfrey, Moore, and Fletcher-Flinn, 2002; Bronfenbrenner, 1974). However, the present findings should be interpreted with caution in the light of some limitations which were noted throughout this project.

4.2. Limitations

Participants represented 15 children which limits the power of this study to detect differences and significant changes. This number is also not big enough to facilitate the generalization of the results. Yet, the number of

participants who attended the course was within the capacity of the people that the service could accommodate and despite its size, results showed significant changes. In addition, these 15 children were all boys thus are not representative of the ASD population. However, given that the gender ratio is 2 boys to 1 girl (e.g. Fombonne and Tidmarsh, 2004) it comes with no surprise that this group happened to represent only boys with ASD. Furthermore, only one measure was used to evaluate pre and post changes. Perhaps the study could have been benefit by the use of more measures to assess parenting skills. However, the APQ was chosen to assess parental behaviour changes because it is a measure which was used in the past successfully and has satisfactory reliability and validity (Andersen et al, 2006). Furthermore, the assessment of the parenting skills could have been evaluated via an additional different route such as home visits from experts before and after the programme. The study could also be enriched by looking into the effects of the improved parenting skills on the child's behaviour. Thus, a measure to evaluate this could have been put into place such as parents' ratings of their childrens' behaviour before and after the programme. It would have been also useful to have further information with regard to this outcome from other informants such as teachers or observations at home and/or school from experts. An additional outcome measure which could have been of interest would have been to look into the parents' mental health status by administering questionnaires such as the Beck Anxiety Inventory (BAI; Beck and Steer, 1990) and Beck Depression Inventory (BDI-II; Beck, Steer, Brown, 1996) to identify symptoms of anxiety or depression. Another limitation of the study is that no follow-up measurements were taken to assess whether the benefits following the course were maintained. Although this would be valuable information to draw more firm conclusions with regard to the course's effectiveness, this was not within the initial purpose of this study. Finally, this project did not have a comparison group in order to conclude whether the findings were

incidental and can only point out changes within the group that participated. Given that this was an initial attempt to evaluate this programme, the design employed – although an elementary one – achieved its purpose. Acquired knowledge from this project can now be used as a base to conduct a more robust and thorough evaluation in due course.

4.3. Future Studies

Future research focusing on evaluating programmes for parents of ASD children could incorporate more measures to assess parenting skills and different assessment methods such as questionnaires and video feedback or home visits from experts. Also, studies could look into the effects on the behaviour of ASD children following the participation of parents to such programmes. The evaluation of this outcome could be enriched by acquiring ratings from different informants such as parents and teachers. Other studies could include assessments of parents' anxiety or depression symptoms and measures on self-efficacy and confidence to manage their children's' behaviour. More rigorous projects could focus on identifying the critical elements of parent focused programmes which are more effective. For example, they could assess whether skills training directly to parents are more effective than the provision of information on ASD or whether video feedback on parenting skills is more effective than general consultations. This will advise the structure of programmes aiming to assist parents of ASD children. Longitudinal studies would be useful to increase knowledge on the long-term value of parent focused programmes. Other studies could research whether there is need for ongoing support for parents to assist them to maintain new skills, and to deal with new challenges coinciding with their child's development. This is particularly relevant given that Moes (1995) reported that information on long-term gains from such parental programmes reveal inconsistent findings with regard to the generalisation and maintenance of the skills acquired by children. Finally, future studies

could aim to develop valid and reliable outcome measures to be used in such evaluations.

4.4. Implications for the service

Despite the limitations of the present study, its findings provided the first evidence for the effectiveness of the three day programme. Therefore, the Child and Adolescent Autism and Related Disorders Service may continue offering this programme to parents of ASD children.

However, based on the qualitative information gathered anecdotally, the main implication of the present project is that the ARD team could consider changes in the structure of the three days programme. For example, an extra day could be added to the course in order to focus specifically on the challenges that parents are facing daily with their child. Parents could be asked beforehand to indicate one specific behavioural problem of their child which they perceive as the most challenging one. The extra day could be structured in the form of a workshop where parents will receive specific behaviour management advice and material, where appropriate, from clinical psychologists. By the end of the workshop, parents will learn a specific way to manage their child's behavioural problem more effectively. They will also benefit by listening to other children's behavioural difficulties and experts' advice on how their parents can deal with them.

Given that this new addition to the service would take place, it would be useful to conduct a study to evaluate its effectiveness. For example, the APQ can be used as a measure to assess changes in parental behaviour. It can be administered at the beginning and at the end of the three day course as well as at the end of the fourth extra day. In addition, it would be useful to have at least a three-month follow-up measurement with the same questionnaire to assess whether any benefits have been maintained. In order to strengthen

the design of such a project and allow for more firm conclusions to be drawn, it would be useful to develop a questionnaire to evaluate qualitatively parents' satisfaction with regard to the extra day of intervention. This questionnaire could comprise of closed and open questions. Closed questions could ask parents to rate qualitatively whether their child's specific behaviour difficult for which they attended the workshop has improved, parental satisfaction of the subjected improvement, whether they found the workshop useful, parental perception as to whether their child's behavioural problem improved because they applied the advice and technique they were given, how often they applied the technique and parental confidence level in managing this specific behavioural problem. Open questions could refer to what parents found useful and what not in the workshop and what changes could take place to improve it. This questionnaire may assist researchers to collect stronger evidence that the specific behavioural problems improved because of the fourth day intervention and improve the structure of the workshop.

4.5. Dissemination of findings

The results of the present study are planned to be disseminated in numerous ways. A summary of the findings will be presented to the multi-disciplinary team of the ARD team along with the provision of a more detailed report. Articles will be written for the Maudsley hospital e-Newsletter to inform other mental health professionals and the public about the programme and to scientific journals who are interested in moving forward services provision for ASD. Finally, a report will be sent to the local clinics and the Bromley Autistic Trust where parents are initially being informed about the programme.

4.6. Conclusion

In conclusion, the present study showed that parents benefited from the provision of information with regard to ASD as their improved APQ scores showed. It also highlighted the need to incorporate in the structure of this programme behavioural management advice to assist parents in managing more effectively their child's specific behavioural problems. The application of this individualistic approach to the programme will add value to the parents' course and will increase participation as it will attract the interest of more parents. Other current services can benefit from incorporating such an approach to their parents' courses.

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APPENDIX

Autism: Parent Questionnaire

Child-code:

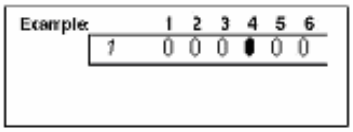
NOTE: This questionnaire takes approximately 10 minutes.
Please set aside 10 minutes to sit down in a quiet place to answer it thoughtfully.

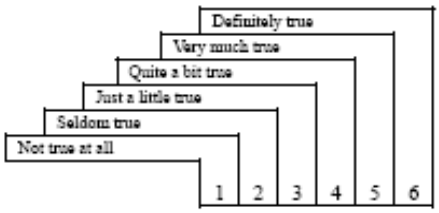
Parenting a child with autism is a challenging job. We are interested in personal experiences, views or beliefs around parenting your child with autism.

Please rate each item according to how TRUE the following statements are for you by using the following scale:

1 = Not true at all
2 = Seldom true
3 = Just a little true
4 = Quite a bit true
5 = Very much true
6 = Definitely true

For each question, fill in *one* bubble completely with black/blue pen or pencil. If you change your mind, put a X through that response, and fill in the *one* bubble you want to be counted.





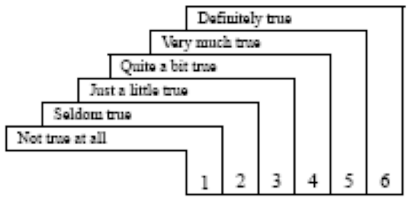
		1	2	3	4	5	6
1	I understand ways in which my child experiences the world differently from children without autism.	0	0	0	0	0	0
2	I understand how autism influences my child's learning.	0	0	0	0	0	0
3	I have a good understanding of why my child communicates the way he/she does.	0	0	0	0	0	0
4	I can reflect on how I communicate with my child and change this accordingly.	0	0	0	0	0	0
5	I warn my child before introducing something new.	0	0	0	0	0	0
6	I match my language to a level my child understands.	0	0	0	0	0	0
7	I wait until my child responds before I say something else.	0	0	0	0	0	0
8	When I talk to my child I give him/her one instruction at a time.	0	0	0	0	0	0
9	I use my facial expression and body language to encourage my child to take turns.	0	0	0	0	0	0

Please return completed questionnaire in the freepost envelope provided to:

Dr Angelika Anderson
Research Centre for Interventions in Teaching and Learning, School of Education,
The University of Auckland, Private Bag 92019 Auckland, New Zealand

I am happy for my questionnaires to be used for research purposes: Yes ☐ No ☐

EarlyBird Parent Questionnaire Form



	1	2	3	4	5	6
10 I know some games that I can play with my child that will teach him.	0	0	0	0	0	0
11 There are some games my child enjoys playing with me.	0	0	0	0	0	0
12 I have a good understanding of why my child misbehaves.	0	0	0	0	0	0
13 I use structure and visual cues to prevent or minimise problem behaviour.	0	0	0	0	0	0
14 I structure daily activities to minimise problem behaviour.	0	0	0	0	0	0
15 When my child has a tantrum I have a number of effective strategies.	0	0	0	0	0	0
16 I am able to change my child's behaviour by the way I react to it.	0	0	0	0	0	0
17 Looking at the triggers and results of my child's behaviour is helpful in managing him/her.	0	0	0	0	0	0
18 My child with autism dominates my life.	0	0	0	0	0	0
19…I feel trapped by the long-term responsibility of having a child with autism.	0	0	0	0	0	0
20…I feel confident that things will improve as I learn more about how to deal with my child.	0	0	0	0	0	0
21 I desperately need more help with parenting my child with autism.	0	0	0	0	0	0
22…I believe that I have some control over the future outcomes for my child.	0	0	0	0	0	0
23…I feel I can improve my child's condition and future prospects.	0	0	0	0	0	0
24 My family functions well as a unit.	0	0	0	0	0	0
25 My child with autism dominates family life	0	0	0	0	0	0
26…The needs of other family members are met most of the time.	0	0	0	0	0	0
27 The people involved in my child's care are in agreement on how to help or manage him/her.	0	0	0	0	0	0

Please return completed questionnaire in the freepost envelope provided to:

Dr Angelika Anderson
Research Centre for Interventions in Teaching and Learning, School of Education,
The University of Auckland, Private Bag 92019 Auckland, New Zealand

SCORING SHEET

Scale	ITEM	Score	
Knowledge	1 – 4	_____	
Communication	5 – 8	_____	
Play	9 – 11	_____	
Behaviour Management	12 – 15	_____	
Stress	16 – 19		⇨ S
		28 – _____	®
			_____
Confidence	20 – 22	_____	
Family Functioning	23 – 25	_____	
Total Score	1 – 25	_____	